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Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS

Cynthia Jones

MAINSTREAM MAGAZINE EDITOR AND PUBLISHER

William Stothers

JOURNALIST AND MANAGING EDITOR OF *MAINSTREAM
MAGAZINE*

Interviews Conducted by
Mary Lou Breslin
and Susan O'Hara
in 1999

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Cynthia Jones (b. 1951), Mainstream Magazine Editor and Publisher: contracting and living with effects of polio; UC San Diego in the sixties, accessibility issues; Episcopal Women's Caucus and other church work; practice of real estate specializing in accessible housing; myths about disability; passage of American with Disabilities Act (ADA) and advising state and national government groups on disability issues; promotion of opportunities for the able disabled through the media. William Stothers (b. 1940), Journalist and Managing Editor of Mainstream Magazine: polio epidemic in the U.S. and Canada; childhood years in rehabilitation hospitals; mainstream schooling and University of Western Ontario; work as journalist for *Globe and Mail*, and *Toronto Star*; University of California, Berkeley, graduate school impact; independent living movement in Canada and U.S.; meeting spouse Cynthia Jones at White House Conference on Handicapped Individuals, 1977; *San Diego Union* career; reflections on Justin Dart, media coverage for people with disabilities, accessibility issues; history of *Mainstream Magazine* and its accomplishments.

Interviewed 1999 by Mary Lou Breslin and Susan O'Hara for the Disability Rights and Independent Living Movement Oral History Series. The Regional Oral History Office, The Bancroft Library, University of California, Berkeley.



Cyndi Jones and William Stothers, March 2000.

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TABLE OF CONTENTS--*Mainstream Magazine: Chronicling National Disability
Politics*

SERIES INTRODUCTION by Simi Linton	i
SERIES HISTORY by Ann Lage and Susan O'Hara	vii
SERIES LIST	xiv
INTERVIEW WITH CYNTHIA JONES <i><u>Mainstream Magazine</u> Editor and Publisher</i>	xix
Table of Contents	xx
INTERVIEW WITH WILLIAM STOTHERS <i>Journalist and Managing Editor of <u>Mainstream Magazine</u></i>	122
Table of Contents	123
TAPE GUIDE	220
INDEX	221

SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbcuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

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New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C., was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

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Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS

Cynthia Jones

MAINSTREAM MAGAZINE EDITOR AND PUBLISHER

An Interview Conducted by
Mary Lou Breslin
in
1999



Cyndi Jones, March 2000.

TABLE OF CONTENTS--Cynthia Jones

INTERVIEW HISTORY	xx
BIOGRAPHICAL INFORMATION	xxii
I GROWING UP AS A DISABLED WOMAN, ACTIVITIES WITHIN THE EPISCOPAL CHURCH, AND MARRIAGE, 1951-1977	1
Birth in Indiana and Onset of Polio at Age Two, 1951	1
March of Dimes Poster Child, 1957	5
Mainstream and Special Education Schools	7
Parental Sacrifices	8
Spinal Fusion at Shriner's Hospital	10
Return to High School in Body Cast	13
Effects of Cast on Back, Teeth, and Eyesight	16
Summer NASA Science Program	18
Easter Seals Camp Paivika	21
High School Experiences	23
Biology Major at University of California, San Diego	25
San Diego Campus Shut-Down and Civil Rights Activities, 1970	30
Swimming and Coed Baseball	34
Lack of Accommodation at UCSD: College Graduation Delayed	35
Involvement With the Episcopal Church, 1973	38
West Coast Coordinator for Episcopal Women's Caucus, 1974	40
Joining <u>Mainstream</u> Magazine, 1976	45
Work Experience Program	48
White House Conference on Handicapped Individuals, 1977	49
Meeting William Stothers and Marriage, 1977	52
Real Estate Licensing Exam and Finding Accessible Housing	55
II RELATIONSHIP WITH <u>MAINSTREAM</u> MAGAZINE AND GROWTH WITHIN THE DISABILITY CIVIL RIGHTS MOVEMENT	58
Practicing Real Estate in San Diego	58
Gays in the Episcopal Ministry	62
<u>Mainstream</u> Funding, 1982	65
Volunteer at <u>Mainstream</u> for Two Years	67
<u>Mainstream</u> , a National Magazine	70
Wheaties Competition, 1984	72
Purchasing <u>Mainstream</u> , 1984	75
First Use of Scooter, 1984	79
Focus on National Disability Issues	80
Sexism at Leadership Conference, 1986	82
Tenth Anniversary Issue Moves Magazine to Higher Level, 1985	88
<u>Mainstream</u> Audience	90
Justin Dart and the Push for the ADA, 1987-1988	92
Meeting With President Bush on ADA Remedies	96
ADA Signing Ceremony at White House, 1990	101
ADA Lawsuit in San Diego	103
Disabled Underrepresented in Media, 1993	104
The Firm Opposes ADA as Local Option	106

Entree to City and County Officials	107
Paralympics in Atlanta, Georgia, 1996	109
Christopher Reeve Announcer	111
Media Sponsor for Paralympics	112
<u>Mainstream</u> Ceases Publication, 1999	115
NIDRR Grant for Center for an Accessible Society, 1999	117
Niece Born With Down's Syndrome	120

INTERVIEW HISTORY--Cynthia (Cyndi) Jones

In various roles including editor, publisher, and president of Mainstream Magazine of the Able-Disabled Cynthia Jones was one of a small number of journalists with disabilities to use the media as a tool to promote opportunities for others with disabilities during the 1980s and 1990s. During its seventeen-year publication, she developed Mainstream from a four-page newsletter to a four-color glossy magazine, using it as a forum to dispel myths about disability and to showcase current issues that were important to the disability rights and independent living movement. Not only was Ms. Jones a practicing journalist, she was also a community activist. She worked with consumer groups around the country on advocacy and empowerment issues and also acted as advisor on disability issues to numerous private, government, and community groups. She was a member of a select group of disability media representatives to discuss disability rights issues with former President George Bush, Sr., on the eve of the passage of the landmark 1990 Americans with Disabilities Act. From her vantage point as a journalist, Ms. Jones observed the disability movement nationally during its formative years, chronicling and documenting many of the most important events that took place in California and nationwide.

Ms. Jones contracted polio as a child. For several years she volunteered as the "poster child" for a national organization that raised money to provide rehabilitation and treatment for such children. When, as an adult, she came to understand disability in a political context, she interpreted that experience as demeaning and as perpetuating the idea that people with disabilities are only worthy of charity and cannot participate in society unless their disabilities are cured. It informed her understanding of the integration and equal opportunity goals of the disability movement and fueled her commitment to her work as a journalist in the disability field.

A longtime resident of San Diego, California, Ms. Jones attended the University of California, San Diego, and served as the West Coast Coordinator of the Episcopal Women's Caucus in the mid-1970s. She also worked as a real estate agent in the late 1970s and early 1980s specializing in wheelchair-accessible housing.

Ms. Jones' interview took place in two sessions, the first on March 11, 1999, and the second on March 14, 1999. Both interviews were conducted in her hotel room at the Berkeley Marina Marriott while she visited the San Francisco Bay Area on business. Throughout the interview Ms. Jones spoke easily and with excellent recall. The interviewer was a colleague of Ms. Jones. The interviews were transcribed by the Regional Oral History Office, lightly edited by project editor Sharon Bonney, and returned to Ms. Jones for review. She lightly edited the final transcript.

Mary Lou Breslin, Interviewer

February 2000
Regional Oral History Office
The Bancroft Library, University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Cynthia Adair Jones

Date of birth 10/1/51 Birthplace Terre Haute, IN

Father's full name George Walker Jones

Occupation Welder Birthplace Rolla, MO

Mother's full name Margaret Serita Jones

Occupation Homemaker Birthplace Omaha, NE

Your spouse William George Stothers II

Occupation Editor Birthplace Detroit, MI

Your children —

2 cats: Nathan & Natasha

Where did you grow up? St Louis 'til 8yr, San Diego

Present community San Diego, CA

Education BA, Biology, UCSD

Occupation(s) Publisher, Real Estate Sales,

Director, Public Relations

Areas of expertise Disability Rights, Disability publication,
Research (Rehabilitation, Medical), Media Coverage
of people with disabilities & their issues.

Other interests or activities Church and access issues,
enforcing the A.D.A.,

Organizations in which you are active Episcopal Church

INTERVIEW WITH CYNTHIA JONES

I GROWING UP AS A DISABLED WOMAN, ACTIVITIES WITHIN THE
EPISCOPAL CHURCH, AND MARRIAGE, 1951-1977

[Interview 1: March 11, 1999] ##¹

Birth in Indiana and Onset of Polio at Age Two, 1951

Breslin: This is Mary Lou Breslin interviewing Cyndi Jones at the Radisson Hotel at the Berkeley Marina.

I think we should start by talking about where you grew up and a little bit about your family. So why don't you start by telling me where you were born and what happened in the early years?

Jones: Okay. I was born in Terre Haute, Indiana, and my dad was a welder with construction projects, so they traveled around from job to job. I happened to be born in Terre Haute, Indiana, because that's where the job was at the time. I have two older sisters and two younger brothers.

After I was born--I'm not exactly sure how long after that--my family moved to Carlsbad, California, which is in southern California, and my dad was working on a construction project. His father, who lived in Rolla, Missouri, was dying. So everybody piled in the car and we headed back to Rolla, Missouri. I got polio [laughs], and that was the way that went.

It was really traumatic for the family, partly because they went from job to job, city to city, but also because I had two older sisters who were very young. They were five and four, or four and three, and they were in nursery school. Because I had polio they weren't allowed to go to school because no one wanted to be around anyone associated with polio. So it meant that not

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

only did my mom have to deal with me being in the hospital, but now she had two little girls that should have had some preschool time who now were not getting that. Furthermore, it was stressful on the family because my mom couldn't go shopping in the grocery stores. They wouldn't let her in the stores because I had polio. The church actually had sent out baskets of food. The church took care of my family during that time.

Breslin: You were two when you got polio?

Jones: Yes.

Breslin: And your two younger sisters--

Jones: They're older than me. They were like three and four. There were three children in three years. Whether they had their birthday just before or after--.

My dad was working, and I was in an iron lung. I was the smallest person, I guess, to have been in an iron lung or whatever, because they had to sandbag it. I was too small.

Breslin: What does sandbagging mean?

Jones: I can't remember exactly. I think they put sandbags in the iron lung because I was too small and I would be sucked in. They had to sandbag me so I would not be sucked into the machine. They needed around-the-clock nursing for me, and my parents were paying as much for my nursing care as my dad was making in a day. So I've always kind of felt--when we were talking about sacrifices--I mean, that's pretty incredible. Today you think about the cost of medical care, but it was different back then. For some reason my parents had like \$5000 worth of polio insurance because in those days people had polio insurance because they were so afraid of getting polio. In the early fifties \$5000 was a lot of money, but that money disappeared real fast.

It was kind of funny because I think about the AIDS [acquired immune deficiency syndrome] epidemics now, and I think it's very similar to the polio epidemics in my day in the early fifties because people didn't want to be around anyone who was associated with polio, and a few years back people didn't want to be around anyone that had anything to do with AIDS. There were a lot of similarities in the fear content.

Breslin: When you recovered from the early stages of polio what sort of situation were you dealing with? What was your level of disability?

Jones: I had pelvic band braces, so I had braces from my waist down both feet. I can't raise my arms. I had a tracheotomy because they had to suction the fluids out of my lungs because I couldn't cough. My spine is fused from top to bottom. That means although I do fairly well, I have a fairly significant disability although it doesn't always look to outsiders as if--. You can't raise your arms, so you don't raise your arms; no one knows that you can't do it because usually I'm not in the position of showing people what I can't do. You try to present yourself in your best light. I get tired.

When I was young--say four or five--what happened was I would go home from physical therapy--the polio cars would pick us up and take us to therapy every day--but my parents were living in a trailer, and they wouldn't come to a trailer. So I was sent to live with my grandmother because she was in a house, and they would come to my grandmother's house.

Breslin: And this was in Terre Haute?

Jones: No, this was in St. Louis after we had moved back there.

Breslin: When did you move to St. Louis?

Jones: Rolla, Missouri, is just like a hundred miles south of St. Louis. So when they went back for what turned out to be my grandfather's funeral, and I got polio, they basically relocated in the St. Louis area.

Breslin: You were saying about the level of disability--

Jones: So I would go into the polio clinics every day and they would walk me around. The thing I remember most is a real stupid exercise they used to do because we'd be on the mats, and they would just--Weebles wobble but they don't fall down? They would basically push you over because they wanted you to know that when you fell you could get up. So we practiced falling and getting up a lot [laughs]. I guess later it was a good practice because when you fall you kind of can position yourself so that you don't get hurt as much as if you hadn't practiced falling. We practiced falling a lot.

The other thing I remember is the long hospital corridors where we practiced walking. They would walk us down these long corridors. To this day I don't want anybody watching me walk. If a gentleman or someone says, "You go first," I hate it. I don't want to go first; I want them to go first. I don't want anyone standing behind me watching me walk. Even if they're not watching, I think they are. It's one of those things [laughter].

Breslin: You were wearing long-leg braces on both legs at that time?

Jones: Yes, I'd come home from the polio clinic, which I think was every day. Maybe it just felt like every day. We'd come home and I'd take off my braces because they're heavy. I was a little kid and these things probably weighed as much as I did. I would come home and take them off and kind of scoot around the floor or whatever. Actually, that was the best thing because it exercised little bits of muscle that was remaining. As a result, I wound up being able to walk. When my mom took me into the doctor's she said, "Cynthia can walk." The doctor said, "No, Cynthia cannot walk without her braces." Mom said, "No, Cynthia can walk without braces." He said, "Well, show me." Here we are again having the doctor watch you walk down this hall. He couldn't believe that I could walk without my braces. It's kind of a trick. Probably I shouldn't be able to but I can. My left leg has what we call a back knee. It basically acts as a brace and it locks just like a brace would lock, only without the brace because you have a back bow in your leg.

Breslin: It's hyperextended.

Jones: Yes, hyperextended.

Breslin: How was your family dealing with your disability?

Jones: I think they were doing okay. The other issue is that my mom was pregnant when I got polio. I think that was really hard. It kind of was hard on them because all of a sudden they were ostracized for no reason of their own. It was hard on them. My dad was spending a lot of money on hospital care. I think it puts a lot of stress on families. If someone's injured today it puts a lot of stress on families. I think a lot of us don't really pay attention to what the dynamics were at that time. I always think about my parents saying, "Oh, it's no big deal." They never talked about how hard it was, but looking back I know it was hard.

We had some family rules--well, that came a little later. One of the rules was that if one of the kids is not welcome, none of you are welcome. I think it was a rule that was established so that I would be able to participate. If I wasn't welcome, no one was welcome. That meant everyone had to come home, whatever the activity was. I never realized that was really a way for me to be included, but it was.

Breslin: Have you thought about that family policy later in life and how it influenced the way you think about the work you've been doing?

Jones: I was playing with the neighborhood kids after school. We'd play softball in the street. It was fun because you modify the rules: reasonable accommodation. The rule was if I hit the ball they couldn't run for the ball until I got my crutches. It was reasonable accommodation.

Breslin: A very early version.

Jones: Yes. And the kids did it themselves; it wasn't the parents making up the rules. We had another rule--we had a six-foot wall around our backyard--the rule was if you hit the ball over the wall it's an out because the neighbors didn't like it [laughs]. Usually you'd think if you hit the ball over the wall it's a home run. You just modify the rules to make it work.

March of Dimes Poster Child, 1957

Breslin: Tell me about going to school. Where did you go to grade school?

Jones: We're going to go back a step. When we were in St. Louis I was a poster child for March of Dimes in 1957. That meant I was six. They make you think you're a queen or a princess. They do a lot of stuff for you and you're the center of attention and a lot of things. We would go to parties and I was basically the star of the event; that's how they want you to be. The way they choose you is because you're smart. Even though you're five or six years old you have to be able to carry on an adult conversation. When people ask you questions you're supposed to be able to answer them. One time I was going to get this doll--it was like a Christmas party. I said, "I need two more dolls." They wondered why I wanted two more dolls. "Because I couldn't go home with a doll and not have dolls for my two sisters. That's not right; they didn't get to go to the party." It was just kind of the way things went.

The thing about being a poster child is that they're using you to raise money. I was poster child at a very critical time in the transition of March of Dimes because I was at the time when the polio vaccine had been found in '54 or '55. This was two years later, and March of Dimes was in crisis because now no one was afraid of getting polio. They were in a panic over their fundraising. The year that I was poster child they had this canister that had three different pieces--it was plastic on a board--one slot was polio, one was birth defects, and one was arthritis. I'm sure that they found which one would raise the most money. That's how they decided which one they were going to

do. The other thought I had about that was that if they picked birth defects, they would never have to find another "cause" because there will never be a cure for birth defects. It will be mutations. Birth defects will happen forever. They're never going to find a cure for every birth defect, so they're never going to be without a cause again. It's kind of Scarlett O'Hara, you know? [chuckles]

That year I was in my class--it was first or second grade--and they passed out this flyer. I remember my teacher saying, "Oh, this flyer has one of our classmates on it!" Of course it was me, it was my picture with the frilly dress and the crutches, and I was in my regular poster-child pose, which is this smiling crippled child. There were these other two kids running down a hill, and over the picture of the kids running down the hill it said "This" and over my picture it said "Not this." I wanted to slump under my desk.

Breslin: This was the first time you saw it?

Jones: Yes. I thought, "I didn't authorize them to use my picture that way." I probably didn't say those words in my head, but this wasn't what they were supposed to use my picture for. I was furious. I went home embarrassed. I thought, "Oh, my God." When I got home I told my mom she had to call March of Dimes and tell them they couldn't use my photos anymore. I think at that point I understood. I understood a lot about March of Dimes; I understood a lot about being disabled. I understood that society didn't want to have a disability. So I internalized. That's because I was smart. They only want smart kids to be poster kids. So it was kind of like because they select someone smart then you put all this stuff together. That was the beginning of my disability rights advocacy. My mom said, "I don't think I have to call them. I don't think they're using your photo any more because your year is up." It was the timing and all that.

Breslin: Did you ever have a chance to talk with any of them about that?

Jones: No. You mean later?

Breslin: Even then.

Jones: I was only six. No.

Just before that happened I was up for what would be the National Poster Child. That's a big deal. They brought the retiring poster child to St. Louis, and we met and shook hands on the plane steps--in those days it was steps up to the plane. It's funny because when you look at the picture of the two of us,

we both look alike. Identical. Except she had dark hair and I had light hair. We looked identical: the same braces, the same frilly dress. They had to keep a child of that age. They had the photographer who came in from New York, and all the photos were taken and everything was done. I wasn't selected as poster child because that was the year they were actually having real difficulty raising money, and that whole family became the poster family that year. It was interesting looking back over that period of transition and being in a position of understanding at that time.

Mainstream and Special Education Schools

Breslin: You were about ready to start school at this stage?

Jones: I was six. I was actually in first or second grade. Then we moved to San Diego.

Breslin: When you were in St. Louis were you in regular schools?

Jones: I was in regular school.

Breslin: How was that?

Jones: Fine. I was smart. I was able to hold my own. I don't remember doing outdoor games and that kind of stuff. I don't remember any of that. Basically you're doing academics and doing well.

My mom had to fight to get me into kindergarten. Not because of my disability--that was part of it--but because my birthday was October 1, and that was the cutoff. The school district was basically saying, "Well, she's on the borderline; let's just wait a year." My mom was saying, "Well, she's on the borderline; let's not wait a year." My mom prevailed and I started kindergarten on time. I don't have really many memories of it.

Breslin: Was the school accessible or was that not an issue for you?

Jones: It wasn't an issue. There were two stories, but the lower grades were on the first floor. So that wasn't an issue. My sisters had classes upstairs. I guess if I had stayed there much longer it would have become an issue, or they would have had to rotate classes down. I don't know. But at the time it wasn't an issue.

Breslin: So you moved to San Diego--

Jones: The summer of '59.

Breslin: And what happened then?

Jones: San Diego had a policy that if you had a disability you would go to the special school which was Sunshine School. Actually, it wasn't just elementary, it went from preschool through 12. I don't want to say all the classes were combined, but they had like first/second as a class, and third/fourth, and fifth/sixth. Then when they got to junior high that was combined, and the high school grades were combined. I hated it there. I wasn't like those other kids [laughs]. "I'm not that disabled. Besides that, I'm smart." It had all ranges of disabilities. I made friends with a couple of kids there that were in the same predicament that I was in, that they had to be at this special school but they really didn't think of themselves as disabled.

The thing that happened at Sunshine School which would never have happened had I not been there was that I met other people with disabilities who were bright. Some of those people I still am in touch with today. Mainstream magazine would have never happened had it not been for Sunshine School.

Breslin: You should just say what Mainstream is, and then we'll go back and we'll talk about it later.

Jones: Mainstream magazine is a national magazine that was started in 1975 because the creator of it actually felt that the community didn't have a voice. It was really interesting because his disability was CP [cerebral palsy], and he had a speech impediment. It was an outward manifestation of his personal disability. But also he believed that the community needed a voice of their own. I met Jim Hammitt at Sunshine School.

Breslin: And remained lifetime friends?

Jones: Yes. Acquaintances. Friends. We went our separate ways, but at certain times at different events in San Diego people would get back together. We'd see each other or whatever. But we're jumping the story, so we'll have to come back to that.

Parental Sacrifices

Breslin: Right. So you escaped Sunshine School at some point.

Jones: The way to escape Sunshine School was that my mother had to learn to drive, because she had to be able to drive me to the neighborhood school. I was at Sunshine for two years--third and fourth grade--and then my mother learned to drive. So I got to go to the regular neighborhood school in fifth and sixth. Thinking back on that, talking about sacrifices your family makes, my mom probably had to drive my dad to the construction site so she'd have a car. The work site might be thirty miles away, and in those days it wasn't like major freeways. Or else, how did they get the second car? At the time, you don't think about that, but looking back you think, "Wow, something happened there."

So I got to go to fifth grade in regular school, and I was bright and I was doing well. Then the teacher pulled me aside one day and she was asking me these stupid questions and I thought, "Lady, you really are dumb." She was asking me why I don't play with the other kids. I'm thinking, "Well, they're way out there on the playground. I'm not going to walk all the way out there." She just had this sense of needing to manipulate the relationships so that I would be included, when in fact I was okay with the way things were. But she wasn't okay with the way things were. So her intervention kind of made things worse. I don't really know exactly what I mean by that, but it was real uncomfortable that she was asking me what seemed to be obvious questions. Why don't I go play tetherball? Well, I can't raise my arms, lady.

Breslin: She wasn't very well-equipped to understand this.

Jones: No. Now I probably shouldn't be so hard on her because I was probably the first disabled child she had ever had in her class, and she was probably doing the best she could [chuckles]. I don't know what would happen today. Regular classroom teachers are probably still as ignorant of kids with disabilities because they still don't have many kids with disabilities because IDEA [Individuals with Disabilities Education Act] hasn't been enforced. How's that? That's my advocacy statement. It's the truth.

Breslin: When your mom decided to start driving and taking you to school, do you remember if there were other issues that came up about whether the school district would allow you to go to that school? Were there other concerns or was it strictly a logistical issue?

Jones: I think that there probably were other issues that I don't know. When parents intercede for children, children aren't always aware of their intercessions. However, I had two older sisters,

remember, that were at that school. I think that my mom made some argument that if anything needed to be done my older sisters could help or I could call home or whatever. For whatever reason they allowed me to come once they had the transportation worked out. There probably were other issues, but I wasn't aware of it.

One thing I did do when I was in sixth grade--a year later--was I learned to play the flute. That's unusual because I have breathing difficulty [laughs]. Maybe that helped me later to expand my lung capacity. I used to drive my parents crazy, practicing flute. I gave that up later for academics [laughter]. There are only so many class times in the day, and when you get to junior high, if you want to take your algebra and your chemistry and your whatever it is you're taking, you don't have enough slots. It kind of fell by the wayside.

Breslin: You have to make your choices at that point.

Jones: Yes.

Breslin: Was the school physically accessible?

Jones: Yes. It was one floor. That's how San Diego schools were at the time. If we had lived somewhere else it wouldn't have been the case, or even in San Diego some of the older schools would have been two-story. But where we lived it was all flat.

Spinal Fusion at Shriner's Hospital

Breslin: You finished grade school and high school in San Diego?

Jones: Yes. I went to Gompers Junior High in San Diego. In ninth grade I went to Shriners Hospital because I had my back fused.

Breslin: How old were you then?

Jones: I don't know--whatever ninth grade is. Thirteen, probably. It must have been 1965. It was the year Watts was burning. The Shriners Hospital in Los Angeles was very close to Watts, and we could see it burning from our window. We could smell it burning, and we could hear the fire engines all the time. Then what happened that was interesting was they threw the fire alarms at the hospital, because I guess that someone figured out that in order to divert the fire engines from Watts so that more could be burned, if you throw the fire alarm at a children's hospital the fire engines go to the hospital. That's exactly what happened.

They had the kids in basically three wards: babies and infants, then younger, and then older teenage kids. What happened was the teenagers were responsible for the middle-age kids, and the nursing staff dealt with the infants. It was an interesting time. I remember The Times They Are A-Changin' was on the radio and really feeling like being a part of what was happening in a very tangible way. Once we got the kids settled down--the hospital wasn't on fire; it was just a false alarm to throw the fire engines our way or whatever--the next night the same thing happened. It was really strategic. I don't remember this going on for nights on end, but it happened for several nights. A couple nights anyway.

Breslin: What prompted you to have such invasive surgery? What was the basis for the back fusion?

Jones: Because of scoliosis. They said it was the right thing to do. I guess I had a corset for a long time, and they said that this would help. [in skeptical voice] I don't know. Doctors think they know everything, but they really don't. In some ways it was better and in some ways it was worse, because once your back is fused you have no joints. Your vertebrae are fused. You think about your back having movement, but then you don't have any movement. Things that you used to use to make things work now don't work.

Breslin: Do you have any memory of that being a difficult time or was that just sort of in the course of things? How was that period for you?

Jones: That's an interesting point, because when I was in Shriners Hospital I wasn't there very long. I went there for like three months during the summer between eighth and ninth grade to have the surgery and get adjusted to this huge body cast that was top heavy, which meant I couldn't walk that year. I was in a body cast for fifteen months, and they changed it twice in that period of time. It was interesting because--I keep saying I was really bright, but here I am in this ward of kids that are--

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Jones: I was teased a lot for being smart. Thinking back, I think it was because these kids really didn't have an education. I don't know what else to say about that. It's really sad now that I think about that, that they were either in special school or were not in school or were homeschooled or whatever they were. I got teased about that a lot. I had my school books in the hospital with me because I didn't want to get behind. I had algebra; I

had to learn this stuff. I couldn't go back a month later. I couldn't have kept up.

Breslin: Did you have any tutoring while you were in the hospital or were you teaching yourself?

Jones: No, I was basically teaching myself. I was just doing the work. I don't know if they had classes in the hospital. I think I went to them once. I think they did have classes. But it was a waste of time. It wasn't worth my going to the classes [laughs], so I didn't. I think I went there a couple of times and then I didn't.

Breslin: So it was optional in terms of the hospital administration.

Jones: I think it was. They weren't teaching me. Maybe they were teaching these other kids because they were at such a remedial level. But they weren't teaching me, and they were probably glad I quit going [chuckles].

This is a weird thing. The kids called me "Creeper," partly because when I was in a wheelchair--I don't have any upper arm strength--I couldn't push a manual chair. It was really weird. It was really sad.

The other thing I remember about being in Shriners Hospital was the Episcopal priest in the area, which is in Los Angeles--I'm from San Diego, it was a hundred miles. The Episcopal priest came to see me one day, and that meant I had to go downstairs and go to the chapel room or whatever it was. He was coming to see me because he had a need to come and do his duty at the hospital. But he had no comprehension of what my life was like or what I was doing in the hospital. I mean, I had a regular routine. He was interrupting my routine. It's funny because I'm a religious person, and I thought, "What are you doing here?" [laughs]

Breslin: He came because he thought you were sick, and you're not.

Jones: I guess. It was very weird. He said, "Is there anything I can do for you?" I said, "Yeah, leave so I can get back to my business." [laughs] I don't think I used the word "business," but I just told him I would appreciate it if he'd leave [laughs]. That's kind of pushy for a kid.

My parents would drive up on the weekends. They would come up on Sunday afternoon, and my brothers and sisters couldn't come in because they had rules against children in the hospitals--even though we weren't sick and they weren't sick--which now the hospitals don't have those kind of rules. So we'd go over to the

windows and look out and shout down to the brothers and sisters. That's hard. They had to drive all the way up here, and in those days a hundred miles probably took four hours. I mean, it wasn't like the real freeways now. It took them all day.

Breslin: Was it hard being away from your family during that three-month period?

Jones: I don't think so. It wasn't like I grieved their loss or whatever. Not that. But when I had surgery, it was interesting because in those days they gave you morphine when you came out of surgery, and my parents and other people sent me cards. When I woke up the nurse would read me the cards or whatever. Then I'd go back to sleep and then I'd wake up and I'd say, "Did I get any mail?" She must have read me the same cards like six times, because you don't know that it's a day passed or three hours or whatever. You have no comprehension. I realized at that point that I would never do drugs or alcohol. Nowadays you think about those things. But in those days I thought, "I don't like not being in control." When you're on morphine you're not in control. It's probably not exactly the words I thought, but I knew I hated not being aware. When I realized this lady had read me the same cards a number of times I thought, "What a dumbshit," you know? [laughter] You make decisions at certain points in your life.

The other thing I want to say about being in Shriners Hospital is the beginning of my weight problem. I was a little overweight when I went in, and the doctor put me on a 500-calorie diet because he thought I should lose weight before my surgery. As we know now, that's not good. It screws up your metabolism. My metabolism has been screwed up ever since. You do this yo-yo dieting stuff--and I actually trace it back to--I mean, I wasn't really overweight at that point, and I probably would have grown out of the little bit of overweight I was. But because of that severe low calorie intake--in fact, the dietician came up to me and said, "For someone on a 500-calorie diet I expected to come up here and see someone grossly overweight. Why does he have you on a 500-calorie diet?"--then it went up to 800. But we know now you really shouldn't go below 1200 when you're trying to lose weight. Learning, learning.

Return to High School in Body Cast

Breslin: That's the 1960s for you.

So you got finished with your fusion. Did you go back to school in a cast?

Jones: Yes. I was in a cast in a wheelchair and the school was flat, but I had to have someone take me to my classes because I couldn't wheel. That was interesting because I was in drama that year as one of my electives. I actually had a roll-on part on the stage. This is wonderful. The teacher, whose name was Mr. Noll, picked a play that had a wheelchair part in it, and I got to play the person in the wheelchair [laughs]. That was kind of nice.

Breslin: Do you think he picked that part because you were his student?

Jones: Yes. The year before that--let me go back once--I was in eighth grade and I was in summer school and had drama. I got to play Puck in Midsummer Night's Dream. I was real embarrassed. Puck is a fairy, an imp, and you wear tights. And I'm really conscious of my body image [laughs]. I was really self-conscious of wearing these tights. I remember that part. I was really good at it. So when I went into ninth grade, when I had the surgery, because he knew I was good at what I was doing he picked a play that I could be a part of.

Breslin: You were wearing your body cast too?

Jones: Yes. Body cast, wheelchair and all. Mrs. Sims. I don't even remember the name of the play.

Another interesting thing that happened in ninth grade is that in San Diego you have sex education in your gym class. Only, disabled kids in those days didn't have gym class because they were excused from gym class. So now the question was, "Well, how am I going to get sex education because I don't have gym class? What are we going to do?" Actually, they did the worst possible thing they could do. They pulled me out of one of my classes so I could have sex education. It was really embarrassing. Why couldn't they just let it go? [chuckles]

Breslin: They pulled you out by yourself?

Jones: Yes, I was in drama. They pulled me out of drama class so I could have sex education [laughs]. They had to tell the teacher what I was doing. I thought, "They could have not done that." [chuckles]. You're a teenager; you're embarrassed enough. Sometimes I guess they don't handle things real well. Now if I was king, or queen, I wouldn't do it that way.

Breslin: Were there other kids with disabilities in the school?

Jones: No, I don't remember any.

Breslin: How was that for you?

Jones: It was okay because I was just a kid. I was just smart and doing my job and studying and doing well. I ran for office and was elected in junior high as secretary or treasurer of the class. They were trying to do a smallpox vaccine campaign, and I orchestrated it for the school. We did better than any other school in the district on vaccinations. We really worked it hard. I guess I was always that way.

Going back to sixth grade, I was in Campfire Girls. I was in regular elementary school in fifth and sixth grade. Each group in Campfire Girls was like ten or twelve girls. I really didn't feel like I belonged because I had been at this special school, and now I was at this regular school, and I really hadn't grown up with these kids. I was kind of an outsider. Not really an outcast but an outsider. Now I was going to Campfire Girls because one of the girls invited me along to come to their group.

We were doing Campfire peanut sales. We had to sell six peanut containers, which is a case. I went home that night and sold the six that first night because my dad was getting a haircut and I went with him to the barber shop and I sold six. I thought, "I should go back to the leader's house and get more peanuts." I proceeded to go back and get more peanuts. This went on for a while. I went door-to-door on my crutches selling peanuts. I kid you not. Today I couldn't do that. But in those days I was able to do that [laughs]. And of course you can imagine the image of this little girl in Campfire Girl clothes on crutches lugging these peanuts [laughs]. I sold a ton of peanuts! I didn't realize the dynamics, of course. And you develop your salesmanship skills doing that.

The Campfire Girls in my group were really competitive, and they weren't going to be outdone by this crippled kid. If I could sell fifty they could sell fifty-one. If I could sell 100, they could sell 101. As a result, our group was the tenth best-selling group in the state of California [laughs]. You think about those implications of disabled worker in the workforce, and what does that do for morale and productivity? Those girls would never have sold as many peanuts had I not been there.

So where were we?

Breslin: Great story. High school.

Effects of Cast on Back, Teeth, and Eyesight

Jones: High school. I got my body cast off in high school. I was in a body cast from the summer before ninth grade through just at the beginning of tenth grade. It was fifteen months. When you're in a body cast for fifteen months, what happens is your muscles atrophy, like in any cast you would be in. The muscles that atrophy when you're in a body cast are your back muscles. So now where they've done your back so that they stop the scoliosis, now you have no muscles to sit up with. I laid down in the car all the way home from the Shriners Hospital after they took off the cast. I couldn't attend school all day. I could not sit up all day. In fact, for about three weeks--maybe a month, I can't remember--I wound up going to the nurse's office and laying down almost every other class or every second class because I couldn't sit up all day. So after three or four weeks it got to be where I could be in class all day.

Breslin: You weren't wearing a corset or back brace?

Jones: Not after that, no.

Breslin: That wasn't suggested.

Jones: No. The thing that happened as a result of being in the body cast, besides the fact that my back muscles had atrophied, was--the way they do the body cast is they stretch your jaw bone and your pelvis. We call it "the rack."

Breslin: Describe it a little bit.

Jones: Okay. What they do is they put you on a table that's not a table. It's a strap that they kind of balance you on, and then they put a harness around your jaw and a harness around your pelvis, and they proceed to stretch you out. They also have things that we call "pushers"--I don't know what they're really called--to push the curves in your back to make you straighter. When they get you to a certain place that they think is about as best as they're going to get you, straight-wise, they cast you that way.

Before the surgery they put me in a cast to see what the proper positions would be and also to get me accustomed to the weight of the cast and working with the cast before I had surgery. Then after the surgery they wait a couple weeks and they put you in a cast and leave you that way for six months. Then you come back and they cut it off and put another one on for the next six months. They tell you you cannot scratch, because

if you cut your skin while you're in a body cast you can get infected. The rules were you could not scratch. One of my rules was that when I got out of that cast, I don't care where I am, if I have an itch I'm scratching. It was something I gave to myself, permission [laughs]. "When you get out of here you can scratch anytime you need to."

Breslin: You never cheated and put the coat hanger down the body cast?

Jones: I never used a coat hanger but I did use a knitting needle [chuckles]. The way I did it was really weird. I leaned backwards on the bed so that my stomach would come away from the cast, and then I would very carefully insert it at the top of the cast--not going down towards the skin but towards the top of the cast so that I wouldn't cut my skin, and then I could rub my stomach pretty much without fear of scratching myself. So yes, I cheated on occasion. You knew you were taking a risk at doing that.

When I got out of the cast, what happened was--funny thing--that my teeth were crooked. When you're in a body cast, you wind up putting your teeth together like this [demonstrates]. You kind of go back in this position because it's ingrained. As a result, my perfectly aligned teeth became unaligned. I was very concerned about that. So my mom took me to an orthodontist, and he said to just keep my mouth open for a month and see if my teeth go back. That's why people have to wear retainers after they have braces. He said, "Just make sure you keep your mouth open. You've been in this 'grit your teeth' mode for so long. Keep your mouth open for the next month and we'll see." I did that, and actually my teeth went pretty much back in alignment after a month or two. On all of my bookcovers I wrote, "Keep your mouth open." People would see that and say, "What do you mean?" It's just a message for me to keep my mouth open. I had to remind myself to do that.

The other thing that happened was I needed glasses after that. That's because you have such eyestrain trying to look.

Breslin: Explain what you're describing.

Jones: Your head is in one position because the cast is up to your jaw.

Breslin: It's holding your head up.

Jones: It's holding your head up. As a result, what happens is you're gritting your teeth but also you can't move your head. So to see, you will hyperextend your eye muscles. As a result, when I got out of the body cast I needed glasses. That was tenth grade.

I didn't really associate the two until later, but I know that that was the case. It kind of makes me mad about doctors because they don't care about what they screw up; all they care about is what they want to fix. Like the orthopedic surgeon: he didn't care that he was throwing my teeth out of alignment or that he was screwing up my vision. All he cared about was that he was fixing my back. I think that's probably the truth of all of the specialties. They don't look at the whole person; they only look at what their piece of it is.

Breslin: What was it like in high school in the last couple of years? Were you dating? Were you involved in extracurricular activities? This was the late sixties, after all.

Jones: I was in tenth and eleventh grade in one high school, and I was in twelfth in another because we moved. This comes back to the flute. I would have played flute in the orchestra in tenth grade, except I wasn't good enough to be first or second chair. In orchestra there are only two flutes, whereas the band has many flutes. I could have been in the band, but I couldn't walk with the band. So you kind of understand this disability thing. I thought, "Well, that's not fair." But I didn't push it; I had enough to do.

Summer NASA Science Program

Jones: I want to go back to ninth grade when I was in the body cast. I was in advanced classes in all the sciences and everything. In the summer between ninth and tenth grade I was in a body cast and I was using a push chair, and I was chosen--I guess you would say--to do this science class during summer at the Fleet Museum in San Diego. It's a big deal. The Fleet Museum--this was upstairs; there were no elevators. It was an old park building. This is craziness. The teacher and a couple of boys would carry me up those steps every day for however long the class was. I can't remember if it was six weeks. We were doing NASA [National Aeronautics and Space Administration] stuff. It was an exciting time for a ninth or tenth grader. We were seeing a lot of stuff that most people didn't get a chance to see. The kids were really bright. They were like the brightest science students from all the junior highs in the city. So it was really fun. When I think about how, my God, these kids carried me up a flight of stairs. Scary.

Breslin: How was it being carried up the stairs?

Jones: I felt a little embarrassed. But I wanted to attend this class, and the class was upstairs, and that's the way it was. You know what? It was okay in those days. Today I never would allow it. Sometimes we make it impossible for ourselves to have experiences because we make rules about our dignity. You have to trade off sometimes: your dignity for your goal. Sometimes you have to say, "How much dignity am I selling? Is it worth it?" [chuckles]

Breslin: In this case it clearly was a good trade.

Jones: A good choice.

In high school did I date? Yes and no. Mostly no. I had a couple of guys that I really liked, and kind of they liked me, but it was weird. I think it has to do with their parents saying the line about, "But she's disabled." I never heard that but you get the feeling that that was going on. One guy whom I had known from elementary school was very bright but very weird. You would call him a computer nerd today. I really wasn't attracted to him but he was very attracted to me. Later I thought, "You can't control who you like, really. It's biological." But on the other hand, looking back, that was kind of hard for him too. Not only being the nerd but he liked the disabled kid in school. It's kind of weird, but I thought that was advanced thinking.

Breslin: He was ahead of his time actually.

Jones: He was ahead of his time, and I didn't give him credit. Now he's a physics professor at UC Santa Barbara [laughs].

Breslin: Sometimes nerds turn into real interesting people.

Tell me a little bit about your high school. This was the late sixties, this was the height of the Vietnam war, and this was sort of the tail end of the height of the civil rights movement. Were any of those things affecting your life in any way that you can remember?

Jones: No. I do remember that the advanced chemistry class was upstairs, and so I got programmed into the second-level chemistry class. That hurt me a lot in the long term. You don't think about that; you think, "You should be glad you're in chemistry or biology," but if you're not in a class that really challenges you, you're not learning at the level you should be learning. Also, if you're not in the top class, which became the AP [Advanced Placement] class, then that means college credits. Long term, it meant I wasn't competing at the very top level that I needed to compete at, and that was detrimental to my career and

my education. You look at that one piece out of all of this. That's too bad. At the time, I didn't really know. I really didn't know I wasn't in the advanced class until I looked around and thought, "All you kids in my geometry class, how come you're not in my science class?" "Oh, we're in the advanced class."

Breslin: You didn't even know until it was too late.

Jones: I didn't know, and then it was really too late. They were doing stuff we weren't doing in the second level.

I dated Larry Adams. Larry Adams was a kid--an adult--from Sunshine School. This was like in high school. We used to go to--oh, this is so embarrassing--a teen club at UCPA [United Cerebral Palsy Association] called Teen Tigers. It was a teen group for disabled kids. When you go to any disability group, there's a disability pecking order. Because we had verbal skills and we were intelligent, we became the leaders of that group. But you know what? You learn to be a leader by leading. By doing that I guess it gave us opportunities later to lead because you have had that experience of leading. We would go to Teen Tigers and go to the dance and all that stuff. My mom would say, "Why are you involved with Larry? He's disabled." I would think, "Well, I'm disabled. Is that what these other guys' mothers were telling them?" I guess because I always do the analysis, I've always been that way, so you say something to me and I analyze not only what you're saying and what the meaning is behind that and what the future meaning is. How does it play?

Breslin: Did you talk to her about what she said to you?

Jones: No.

Breslin: Have you talked about it later in life?

Jones: No. When I met Bill [William Stothers], who has a severe disability, my mom didn't say anything about that. So either she had grown or it was a non-issue. At that point there was really not a need to talk about that.

In high school I tried out--we talked about before that I had been in drama at this other school--I tried out for the part in Glass Menagerie. Obviously, I am the person to play that part. That's my role. I didn't get it. I was so pissed.

Breslin: You're born again Blanche.

Jones: I couldn't believe I wasn't getting that role. But the truth was I had moved into this new school district for senior year, and

the popular girl got the role. That was the way it went at Poway High School.

The other thing that happened at Poway High was my first day there, my senior year. You know, I'm short, and they didn't know me because I hadn't been there before. I go in and they have the opening assembly on the first day of school, and I sit in the senior section because I'm a senior. These senior boys were teasing me, saying, "What are these freshmen doing sitting in these seats?" I just kept my mouth shut because I thought, "I have a right to be here, this is where I'm supposed to sit, I'm a senior." So then the first class period was physics, and I was sitting next to them in physics [chuckles]. It was enough said.

When we went to do our senior yearbook stuff, I bought my yearbook at the beginning of the year--you buy them up front--but when I went to pick mine up, mine didn't have my name on it. All the seniors had their names engraved on their book. I didn't want to pick up the book because it didn't have my name on it. At the time I paid for my senior yearbook they thought I was a freshman [laughs]. So they didn't put my money in the right pile. I told the school that they had to go get mine engraved just like everybody else, and they said they couldn't do it because it was all over. I was pretty annoyed. I thought, "That's not really fair."

Easter Seals Camp Paivika

Jones: In senior high I went to Camp Paivika, which was an Easter Seals camp. I went there between my sophomore and junior year, and I went there between my junior and senior year. The thing about Camp Paivika is it's interesting that you can go to a camp for two weeks where it's all disabled except for the counseling staff--the counseling staff is never disabled--and you have this sense of not being disabled because everybody's disabled, so there's an equalizing factor that happens.

Breslin: It's a sense of not being different.

Jones: Of not being different. Thank you.

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Breslin: You were talking about Camp Paivika.

Jones: Yes. Because everybody's disabled no one's disabled. I guess that's the way to put that. Disability's not an issue. I did think about why they weren't hiring disabled counselors. They should have been hiring disabled counselors. In fact, the second year I went they did have a disabled counselor named Terry Wetzel. He had had CP, and he had been a camper there and grew up through the ranks. Today he is one of the directors or something of the L.A. Unified School District's special education program. He's a good guy. That was important for all of us because--this sounds so weird--we knew we could make it. If Terry could break through that barrier, so could we. It sounds weird, huh?

Breslin: Why do you think it sounds weird?

Jones: It's like we didn't have any role models. None of our teachers were ever disabled. We never saw anybody disabled in a role of authority or power or influence. That was an important thing. I'm thankful that they did that. They should have done it sooner, and they should have more.

Breslin: Did you realize the importance of that kind of a role model then or have you realized it only later?

Jones: I knew it then. I probably didn't verbalize it, but I knew it was important then that he could make it. The fact that if he could make it then any of us could make it. I think that was a real important thing that happened.

When I got back my senior year, I was new at Poway High, no one knew I was a senior. Oh, it was awful. It was awful because all these kids--Poway High is like this little rural community--so these kids had grown up from kindergarten together. There was only one high school in the district. So it was real clique-ish. And I'm the only disabled kid at the school. That was real difficult. Also I was just coming off this experience of being at Paivika where disability didn't matter, and now I was the only disabled person there. So I was really aware. The difference between night and day. I guess coming from an experience where disability didn't matter or wasn't visible--because everybody had a disability so it meant it was truly invisible--then you come to a situation where it's very tough. It was very tough. I was very aware of the differences.

In senior year we went to see 2001: A Space Odyssey. That was a big deal. We went on a field trip. I only bring that up because it's so cultural--and we're coming into 2000, and Hal the computer--it was like a senior sociology class or something. I don't remember how they did it. But all the seniors or whatever

went down to watch this movie. It was good. Just kind of an aside.

Breslin: Let's go back just a minute to my earlier question about the civil rights movement and the Vietnam war and whatnot. Were those national events having any impact on your community that you can remember, or was San Diego pretty isolated from that?

Jones: No, but I graduated in '69. Mostly in college is where it affected me.

I went to the prom my senior year. My sister arranged a date for me. It was very awkward. Looking back, probably I'm glad I went but it was very awkward. It was like May or June of my senior year, and I was at home making dinner. I don't know where my mom was. Maybe shopping or something. I got this call from this woman at Poway High, and she said she was so-and-so the head of the PTA, and asked if I was coming to the awards assembly that night? I said, "No, I'm not. Should I be?" She said, "Yes, I think you should be." [begins to cry] I don't know why I'm getting emotional on this.

Breslin: It's okay. Do you want to take a break?

Jones: No. So I got a \$400 scholarship. I had been accepted to UCSD [University of California at San Diego]. This wasn't money for tuition; it was just money for books.

Breslin: You didn't know about that beforehand. Who was the scholarship from?

Jones: The PTA. The top senior boy and the top senior girl got these two \$400 awards.

Breslin: Which was a lot of money in those days, too.

Jones: In '69 it was a lot of money. It's probably worth like \$1500 or \$2000 today. It was a sizable chunk. I hadn't planned on going to the awards ceremony because I wasn't getting any awards.

High School Experiences

Breslin: The last year in high school was difficult because of the change in schools and all. Did you feel like you had a generally pretty good experience in high school?

Jones: Yes. I think it would have been better had I not changed in my senior year. That was really hard. Now I never go back to reunions because I'm not sure which reunion I should go to. I mean, my real school was the other school. So it was kind of awkward. Then my friends were from the other school, and I had to drive in--that was like thirty miles, and that's a long way in those days--I think that was hard.

Breslin: Was the high school you attended in your senior year accessible?

Jones: Yes. Same as before. For some reason, I guess San Diego schools are all kind of flat, one level. That helps.

I took driver's training. I drove a car in my senior year. The way they did this was it would be a teacher and three students. What you did was you went out on a Saturday morning and you drove for like six hours or four hours or whatever. It seemed like all day. You stopped somewhere for lunch and you'd get in the car and drive back. But this was more than one day worth. I remember this one Saturday we did this. I was driving, and the teacher was in the passenger side and he said, "Why don't you change the radio station?"

Breslin: You can't do that [laughter].

Jones: I said, "If you want it changed, change it yourself." He said, "You're the driver." I said, "Yes, and I'm in control of it and I'm not going to do that right now." I really felt in control. He was asking me to do something that was unsafe. He didn't realize it because I can't raise my arms, I can't extend my reach.

Breslin: He didn't understand that that was going on, did he?

Jones: No. I just told him to change it himself. He wasn't used to students telling him--

Breslin: I'm sure he wasn't used to being told no.

Jones: Yes. So I felt pretty good about that, actually, at the time and afterwards. I thought, "That was the right thing to do. That was not safe." He certainly shouldn't be asking me to do something unsafe. But he really didn't realize it was unsafe. I knew it was.

Breslin: Do you think that he was actually thinking about you as a student without really appreciating overall--

Jones: How disabled I was? [laughter] I'm sure that if he really--

Breslin: It never occurred to him that maybe you might not be able to press the pedals with your feet.

Jones: No, he probably didn't realize. Thank God.

Breslin: Fool them when you can, that's our motto! [laughter]

Jones: It's interesting to think about taking control of your disability. I knew I couldn't do that task. For me to attempt it, it would have been unsafe, but he didn't know that. So yes, fool them when you can.

Biology Major at University of California, San Diego

Breslin: When you were in high school, sort of toward the end of high school, were you thinking at all about what you might want to do?

Jones: Yes, I thought I wanted to go to med school. I had been accepted to UCSD. I guess I was going to be a biology major, which is what I wound up being. I was investigating stuff. I thought I could be a pathologist. I knew I couldn't be a surgeon because I couldn't stand up and I couldn't do this stuff with my hands the way I needed to. But I thought there would be some place like a research-medical type of person.

I wrote my application to UCSD the fall of my senior year. It was interesting because it never occurred to me--now this is naive--that they could deny me on the basis of my disability. They could've. Absolutely. In those days there was no 504. It didn't dawn on me that they could have or would have. The other thing about UCSD that's interesting is--it's actually at La Jolla--is that my dad helped build that school. He was a welder. So I used to go out there when I was in junior high when he was building the school--not that I ever was on the campus much--but it had this emotional attachment because my dad helped build that school. It sounds funny because you think of research people building a school, but he literally built the school. That was kind of an attachment there, and I think my dad was proud that I went there.

Breslin: What made you decide to go there?

Jones: I think it was close. I stayed in the dorms; I didn't stay at home. I decided early on that I would go away to college even though it was only thirty miles, but I wasn't going to commute every day. I told my mom that I was going to go away, and she

was kind of hurt that I wasn't going to stay at home, but I knew I needed to do that. I lived in the dorms.

The way I did that was, Larry Adams--one of my Sunshine School friends--told me how to get on SSI [Supplemental Security Income] and to apply for vocational rehabilitation, so that they would pay for my college tuition. In those days the UC system was very inexpensive. I think the first quarter at UCSD was fifty dollars tuition. But VR would pay for it. The problem was you're not eligible for voc rehab until you're eighteen, and I didn't turn eighteen until after I was at UCSD because I didn't turn eighteen until October 1. So there was this thing how they weren't going to qualify me for voc rehab because I wasn't eighteen yet. I don't know how we worked that through. They gave me an IQ test and they said, "Well, I guess we should put this person through college," and they made it happen. I remember SSI paid for my board and room and voc rehab paid for my tuition, and voc rehab actually sent me twenty dollars a month for incidental expenses. Twenty dollars a month was a lot of money back then. It was kind of nice--this little pocket of spending money. I also had an account at the bookstore so that they would buy--I can't remember what the amount was--but up to a certain dollar volume they would buy the books for my classes each quarter.

UCSD at the time only had three colleges. Only two that were built. They had Revelle, which was the first college, and that was where I was at, which is the science school. They had Muir, which is more the social sciences, and they had Third College, which is what it was called, and now I think it's called Thurgood Marshall College. But it was called Third College at the time, and it was in the Marine barracks.

They also had what we called the "Not So Central" Library. What really is called the Central Library was going to be in the middle of what was going to be twelve colleges. So they put it in the middle of the twelve colleges before the twelve colleges were built. So it was way the heck out there, and I almost never went to Central Library--or as we called it--the "Not So Central" Library.

I applied to UCSD, I sent in the application, and you have this essay about who you are and why you want to go and all this stuff. I went to freshman orientation in the summer. This was the science school. Science nerds. There was no social life at UCSD in those days; there probably still isn't. But in those days there really wasn't. So I guess I fit right in [laughs].

The weekend I was at freshman orientation that summer was the week they landed on the moon in '69. To be in the middle of all these science freaks and to have them landing on the moon, it was really very exciting. That was really something.

I always arranged my classes by where I could get to class. Classes at UCSD were not like high school. They had upstairs and downstairs and they were spread out, so I would never be able to pick my classes by who was teaching the class. I had to pick my class by where I could get to and when it was being taught.

Breslin: There was no disabled students' service center.

Jones: Are you kidding? [laughs] I know, this is for historical purposes when everybody takes it for granted. No, there were no disabled student services. I wasn't the only disabled student on campus. There was a blind young man named Joey [Joseph] Renzi, whom I had actually known from elementary school but we had gone our separate ways, and I guess he had gone to some school for the blind or whatever. But he was brilliant. There was another gentleman who was visually impaired. His name was Rick Tryon, and he was a very smart person as well. That was it. There were three of us.

Breslin: Three that you knew about, anyway.

Jones: Three that had enough disability that you would think they were disabled. There was no one in a wheelchair at school because I was still walking with crutches.

My sophomore year I tore a ligament in a knee. It was the Saturday before finals and I was in the choir. They had the university chorus, and I was in the university chorus because at UCSD you're supposed to be a renaissance person. You had to take something of everything. You have to be art and science and music and math. The requirements for the first two years are such that you're supposed to be a well-rounded person. What they were trying to do was make these science freaks well-rounded, so you have to take something of everything. So to get my art credits I took university chorus for a year. So we were having a performance on Saturday before finals week; that was like the final in that class. As I was coming out of the shower I slipped and I fell. I tore a ligament in my knee, but I didn't really realize how bad it was. Maybe it wasn't fully torn, but it was very painful. I couldn't walk on it. By the end of the day I was in excruciating pain.

I went through and did the performance because I had to get my grade. Then on Monday I totally took the day off and went to

an orthopedist because I knew I had done something very bad to my knee. Because I have polio knees they didn't know what I had done. They didn't know what it should look like, so they didn't know what was wrong with it. He said to just go home and stay off of it for six months. That was kind of the answer. He gave me these painkillers, and I was propping my leg up trying not to move it. Every time I moved it it was excruciating.

On Tuesday I had a chemistry final, so I called the professor's office. I wasn't asking to postpone the test; what I was asking for--which I thought was reasonable--was another girl in my dorm rooms had the same final. But the way they did these tests was they put you in different rooms so you couldn't cheat. So I asked if we could take the final in the same class so she could take me to the final, and he said no. So she had to push me to my room and then she had to run over to her room. Then when she was done she came back and got me. I guess it's not bad, but they didn't need to make it hard.

The next quarter I was using a wheelchair because I couldn't walk. I used the wheelchair the whole next quarter. The professor saw me and said--it's like a light bulb went off in his head all of a sudden--"Were you the one who called me last quarter?" I said, "Yes." He said, "What did I tell you?" I said, "You said no. We had to go to different rooms." It was like an eye opener for him, that I was asking for reasonable accommodation.

Breslin: He didn't put it together until he saw you in the chair later.

Jones: I could have actually asked to have the final postponed. I was on painkillers. I had been out of it, you know? I wasn't asking to put off the test; I was just asking to take it in what was reasonable--.

Breslin: And not any real change in any important way.

Jones: No, it wasn't. He didn't have to do anything. All he had to do was allow one extra person in one room. He could have even put us at different sides of the room. Anyway, that was the way that went, because it was done alphabetical or whatever it was done.

Breslin: Were you spending summers at home during college?

Jones: No. I rented an apartment with some friends and I did telephone soliciting for the leukemia society, calling people. That was okay. It was a job. Actually, it was good because most kids with disabilities don't get jobs. I was paid minimum wage and I

did a pretty good job at it. It was a pretty mindless task. That was unfortunate.

I was the first person in my family to go to college. Well, my older sister had gone but--she did graduate--I don't mean that. My parents had never gone to college; they didn't even finish high school. So I didn't really realize how important certain things were. My goal was to get to college and graduate college. My goal was not to become a graduate student. In my freshman year I gave up the medical thing because I knew I would never get into medical school.

Breslin: Were you sure about that? What made you think that that was true?

Jones: Because it was so competitive. I felt that I was going to be discriminated against. That's the only way to put it. I felt that that wasn't going to happen. It wasn't worth my time because the likelihood of me getting into medical school was marginal. How's that for an analytical way to put it?

Breslin: You don't have any evidence to support that. You didn't necessarily know that it was true.

Jones: I didn't know any doctors with disabilities.

Breslin: But you wanted to be a researcher.

Jones: I didn't know any of them either.

Breslin: Did you know any of them anyway?

Jones: Well, teachers in my school weren't disabled, and the teachers at UCSD weren't disabled.

Breslin: Did you talk to anybody about this or was this just something that you--

Jones: By thought.

Breslin: You kind of thought it up.

Jones: Yes. I just thought that I wouldn't be accepted.

San Diego Campus Shut-down and Civil Rights Activities, 1970

Breslin: When you came to that realization, did you change your career direction or did you decide to take other courses or--

Jones: No. Then I didn't know what I was going to do. I was kind of like a ship without a rudder.

But I was going back to was my freshman year. You were asking this earlier about the civil rights stuff.

Breslin: Yes, the political and cultural--.

Jones: Okay. UCSD in the spring of '70 shut down. All the classes became pass/fail because a lot of the classes were canceled that quarter. I had friends up at UC Santa Barbara, and it was burning. Kent State happened and students were shot. All hell broke loose on the campus when that happened. It was scary. There was a Santana concert at UCSD one Friday or Saturday night and we were living in the dorms. All of a sudden there was police everywhere on campus in full riot gear. The kids from this concert were running through the campus--not all of them were students from UCSD--but that was where the concert was. They were running through the campus, and some of them were coming up into the dorms trying to get away from the police. It was very scary.

I remember one night my roommate woke up screaming because she was having nightmares about this stuff. I looked out the window because she was saying something about the police, and it was perfectly calm [chuckles]; there was nothing out there that night. But because this stuff had been happening--.

Again, going back to fire drills--kind of the story of my life--people were throwing the fire alarms in certain buildings, and so we had to clear out of the building. It meant that we couldn't study for exams because we couldn't be in the dorms. You have to understand that UCSD Revelle students are weird. They were studying by candlelight in the stairwells. They weren't ready to give up the fact that they were not going to be able to study for these exams. You weren't sleeping at night because people were flipping the alarms. It was really, really difficult.

Breslin: Was the student group that you were hanging around with politically active?

Jones: No.

Breslin: These are kids that are really wanting to go forward then, not being interested in the--

Jones: Yes. They are focused on their future. Then a couple things happened, one of which really changed my life, and that was George Winney. What's the word for it when you burn yourself to death?

Breslin: Immolate?

Jones: He immolated himself. The sign was "In God's name, end the war."

Breslin: The sign that was found by him?

Jones: Yes.

Breslin: I'm sorry, who was George Winney?

Jones: He was a student at UCSD. He did that in the middle of the plaza. It was very frightening. I thought a couple things. For one thing, suicide at UCSD was kind of regular. People would go to the top of Urey Hall and jump off. That's what happens. Seven stories. They do that for a number of reasons because of their internal pressure and external pressure. In some ways this was another suicide, but it really wasn't suicide. Then I thought, "What if someone was actually able to talk to this person? Would he have done this?" Nobody talked to anybody at UCSD. They just did their studies. I was really concerned because I thought that if maybe somebody had been available to talk with him he wouldn't have done this. I wasn't looking at the politics of it; I was just looking at the dynamics in the campus and how everybody was so focused on their studies that nobody had time to talk to anybody.

So it kind of switched in my head that it wasn't that important. It's more important that if someone needed someone to talk to, that I would be available. I know I consciously made that decision at that time, which did affect the future of my life because I was not quite as focused on my studies, and I was available for people who needed to talk. Not everybody--I don't mean that--but it just was a different mindset.

Breslin: Did you have a viewpoint about his reason for killing himself?

Jones: Not really. I knew that the draft was there and they had the drawing for the numbers. The other thing that happened the weekend that he committed the self-immolation was that my sister was getting married on Saturday--and this was Friday or Thursday --I can't remember the timing exactly. But I had to get off

campus. In fact I literally walked off campus and had my dad pick me up off campus because they were closing the campus down, and I was afraid that if I didn't leave I wouldn't be able to get to the wedding. Basically the campus was shut down for that time.

Breslin: What was the reason for shutting it down?

Jones: I think they were concerned about more riots and stuff. Then the classes went pass/fail; they quit holding classes. It was really weird. It certainly wasn't what we all had come here for.

Breslin: You and your friends were not part of the underlying reason why that was going on?

Jones: No. I mean, Angela Davis was at UCSD. But that was a very small group of people. Most of the people at Revelle were science people and they weren't involved in the politics.

Breslin: Were there minority students on campus?

Jones: Few.

Breslin: Any that you knew in your social group?

Jones: No. No disabled kids, no minorities. Not that I know of.

Breslin: Had the civil rights movement gotten to your radar at that point in your life?

Jones: Yes, because I watched Watts burn.

Breslin: What did you think that was about?

Jones: I thought that was about the fact that Bobby Kennedy was shot, and Martin Luther King, Jr., was shot, and [President] John F. Kennedy was shot. I was aware of all of that. And the civil rights movement, I knew that that meant--

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Breslin: You were talking about--

Jones: Civil rights and what I know about it. I went to Gompers Junior High, which is basically an inner-city, black school. I knew that I was in advanced classes at Gompers Junior High, and the advanced classes had 50 percent white students and 50 percent black students in what would otherwise be a 95 percent black school. So why was it that the black students weren't majority

in that class? I understood that stuff. I understood discrimination way back. I cried when Martin Luther King, Jr., was shot. I couldn't believe what was happening. I cried when Bobby Kennedy was shot. I was watching that--I'm a Californian--I was watching the election returns, and as he's going through the kitchen he got shot. I was a junior in high school. Most juniors in high school weren't watching the primary results in California [laughs].

Breslin: The reason I'm asking the question is, for some people who are our age, at some point there's a realization that there's some common ground between experiences of minorities and the experiences of people with disabilities. Sometimes it doesn't happen until much later, and sometimes it's some kind of moment in high school or college when it occurs. I was just wondering if you had some sense of it at that point.

Jones: I don't know how to explain it because I went to a minority junior high. I was more one with the black students than the white students. It's not like something that was an "aha!" experience. When I say some of my best friends were black, that was the truth. Sometimes I could see what was going on. I just knew what was happening. Here's the mathematician in me that says, "How come in my math class more than half of the students were white?" That shouldn't be. That wasn't right. Just by numbers, it wasn't right.

This was an experience in high school, it's kind of similar but not really. Because I didn't do gym, they always had me do some other class for the gym period. It was stupid, right? Why don't I just take another academic class? It would be better for me. But no. This one year--I think it was my junior year--they had me working with what we would call the "slow learners" class. Not really special ed, but today you would call it learning disabled. But in those days it wasn't called that. So I, as a disabled kid who was in the advanced classes, was tutoring these kids in the slow class. And that was perfectly fine; I was able to do it. What I learned was that when I go into the class, they were doing this stupid exercise. I thought, "Why is this teacher having these people do this stupid exercise?" It was really stupid. She would sit over there, and I would do this thing with flash cards with these students. I thought, "This isn't helping these kids learn." I was angry. Just because they were slow didn't mean they didn't deserve a quality education. What I learned was they gave us, the bright students, the best teachers. They gave them the worst teachers. The bright students could learn from anybody.

Breslin: Or each other.

Jones: Or each other. I mean, it was these kids that needed the best teachers. What did they have? They had a teacher sitting there reading the paper or something--I can't remember what she was doing--but it certainly wasn't helpful. I thought, "I'm a junior in high school and I'm really the teacher in this class." I've always kind of seen the opposites of things. I guess maybe the way I associate that with the racial question is most of the students in that class were black. Why was that? Because they didn't get the opportunity when they were in elementary school? That goes all the way up. At UCSD I don't remember any black kids. There might have been some Hispanics, there may have been some Asians, probably. There probably were a few, but there certainly were not many people of color. There were not that many women, either [laughs].

Swimming and Coed Baseball

Breslin: That was my next question, whether you remember the role of gender in your experiences, particularly in college in a science program.

Jones: I would say that it was probably three to two: three guys to two women. It might have been three to one. It was certainly male-dominated.

Interestingly, my freshman year at UCSD I learned to swim. Burt Kobiachi, an ichthyologist, was--I'm not sure how they worked this out--but some of these professors of sciences taught gym. There was no basketball program or football program [chuckles]; there wasn't any of that.

Breslin: They didn't really put a lot of emphasis on their athletic program, probably.

Jones: Not at all. Actually that worked out pretty well for me. But I went down and took swimming. I learned to swim at that school and I actually got my intermediate swimming badge. They didn't say, "You have to go to the special adapted swimming class"; they didn't have any of those. They barely had a swimming class. That way, once I was on campus, I was never denied. If I signed up and I could get there--

Breslin: Nobody said no as long you didn't need any reasonable accommodation [laughter].

Jones: As long as you didn't need any reasonable accommodation it was fine. That's right. That's a good way to put that.

One day in spring--I think it was my sophomore year; I'm just picking some of these examples, I hope that's okay with you --I think it was over Memorial Day weekend, because for some reason there were not many people on campus. It must have been Memorial Day because it was in April or May. They had this coed baseball league, all the different dorms and everything. I guess it was actually one of the only social mixers at UCSD. The thing was is that because a lot of the girls had gone home for the weekend, there weren't enough girls. If they didn't have one more girl they would forfeit the game.

Breslin: I can see where this is going.

Jones: [laughs] They said, "Why don't you come play baseball?" I did play baseball as a kid in the street. But here we are at UCSD and of course just hit it to the crippled kid; she can't chase the ball. They didn't really care what my position was, only that I was on the field [laughs].

Breslin: Numbers were the important thing.

Jones: It was important because without another female person they couldn't play the game. That would have meant seventeen people wouldn't be able to play this game because they didn't have another female on the field. So for whatever reason, I played one game of college coed baseball [laughs]. Now in most places that wouldn't happen. So it was kind of an interesting experience. Only at UCSD.

Lack of Accommodation at UCSD: College Graduation Delayed

Breslin: I'm thinking about the last couple of years in college, and you were having to think about what was next. What was on your mind in those years?

Jones: Junior year was pretty much pro forma and then I got to my senior year, and a couple things--. The way this worked was everybody in biology had certain classes they had to take--the core classes. Basically three core classes each quarter and then you had one elective or something. So my middle quarter, my winter quarter, I had to take cell biology, biochemistry, and molecular biology in one quarter. All of the bio students had to take all

three of those classes. That would have been fine had they just had us all sit in one room for three hours.

Breslin: You had to traipse around.

Jones: Yes. It was the middle class that went across campus. We called Muir--which was the other side of campus--the mud puddle, because to get there you had to go through a mud puddle because there was no concrete there yet. They hadn't finished it. So I had ten minutes to go from one end of the campus to the other. I was walking, and there was no services at the time. Then we went from Room A all the way across campus, had a lecture there, and then all the way back to Room A again. So everybody was going from here to there and back--the same group of kids. I did this for about two weeks and I realized I wasn't learning because I was so exhausted by the time I got there, that the last two classes were wasted. I couldn't concentrate. I went to the dean and said, "I think it would be helpful if you would move the middle class back to this room, and then everybody would just stay put for three hours. Nine o'clock, ten o'clock, eleven o'clock, everybody would just stay in their same seat." She said, "We can't do that because we would have to move 500 students," because there were 250 in this class and 250 in that class. I said, "Yes, and all 500 students would love you." They said, "Well, we can't do that." So I realized that that wasn't going to happen. I thought they were being unreasonable. But there was no law.

Breslin: Did you say to her that you were really having trouble personally?

Jones: Yes. I said I couldn't make it to class, that I can't walk--. She said, "We can't move these classes because it would involve us moving 500 students." So that was the end of that discussion. Maybe it was the first week, and then I did it another week, and I realized that I wasn't going to make this. So I dropped out of two of the classes because by that time I was so far behind in my second and third class. Two weeks doesn't sound like a lot, but at UCSD it's like impossible. So I dropped out of two classes, which meant I wouldn't graduate that year because those were core classes and you needed those two classes to get to the next quarter. That decision bumped me out a year. I took it easy that quarter, except I was really pissed.

A friend of mine from UCSD, Stan, was going up to Oregon, and he asked me if I'd like to go up there over Easter break, and I said sure. I had dropped out of spring quarter because there was no point in going to spring semester because I couldn't take the classes I needed to take. So now I was off spring semester.

I went up to Oregon and back, and he was doing something in L.A. called Project SEED, which was Special Elementary Education for the Disadvantaged. This was in Watts--that connection back to Watts. What he was doing there was teaching algebra to third graders. The idea was that students were taught that they couldn't learn.

So this program was remedial in a way because it was teaching really remedial arithmetic but couched in algebraic language--triangles and squares and circles and stuff. On one hand we were teaching them basic arithmetic but having it look like algebra. In fact, it was algebra on a very basic level. As a result, what we were really doing was teaching these kids that they could learn and building their self-esteem that they could learn algebra and they were only third graders. It was a really positive thing that was happening. After a couple weeks there I wound up teaching in the program, the last six weeks of that school year since I wasn't in college. It was one of my best-paid jobs: \$13.50 an hour [chuckles]. In '73 that was pretty good money. That was really good.

In my last couple of weeks there, in June, I was teaching in one of the classes--I don't remember the school's names or anything--but in this one class the teacher had been sitting over in the corner every day reading the L.A. Times, every time I'm in the class. The teacher had to be there because we weren't licensed teachers. What was happening was he was reading the L.A. Times and all of a sudden I called on one of his students and they answered this question which was really complicated, and all of a sudden this teacher looks up, like, "Latasha, you can answer that question?!" The sad part was this was June. He'd written these students off all year, and here we are in June. That's a lot like what happens with special education students too. They get written off because they think they can't learn. That's what this teacher had thought about these students. I'm always thinking about how it all plays out. I did that for my spring quarter of '73.

Then I didn't go back in the fall semester of '74 to teach there even though I wasn't really picking up in my studies again until winter because I felt that they shouldn't have white teachers teaching in Watts to be role models for black students. I felt that they should have black teachers teaching in Watts to be role models for black students. Same thing with Terry Wetzell. We need to know we can do it because we see disabled people succeeding. Black children need to see black role models succeeding. So I just didn't feel comfortable. It was okay for me to have that experience but it really wasn't the best for these students.

Involvement with the Episcopal Church, 1973

Jones: So I took off, and one thing I did was I went to the general convention of the Episcopal Church in 1973 in Louisville. We went there and I was just a college student and there was a college presence at the convention. We were watching a couple of issues. One was women's ordination to the diaconate and priesthood, and that got defeated in '73. There was another thing called the youth special convention, the youth program, which was how the Episcopal Church was dealing with high school and college students, because they were dropping out of the church, and this was a way to keep them in. But it got so political because when the youth in this time--the early seventies, late sixties--were making decisions about where the church should spend this special pot of money, it was very radical stuff. The powers-that-be in the church got very conservative. So the church ended that program. It was really political. They had funded some really wonderful things, but that got canned.

A result of my involvement at the convention was that I was invited back to New York the following year to meet with the new presiding bishop of the Episcopal Church, because he wanted to know how the church could be more open to young adults. But he really didn't want to listen to us, which was why he was bringing us back there. He just wanted to have it on his checklist that he had talked with us. What happened is that we flew back there for this token visit, and he wanted to know about a church Peace Corps kind of thing, and really what the youth wanted was to be included at the local level into their church. Not that they wanted to go away and do a Peace Corps kind of experience for the church. They didn't want to be missionaries for the Episcopal Church; they wanted to be valued where they were. The church never got that; they still haven't got that. Then I went back to school.

My major is in biology, my minor is in religious studies. At UCSD you have to have what's called a non-contiguous minor, meaning you can't have science and math; you have to have science and something else. Or math and something else. I actually got to do a lot of studies about Native American cultures and their religions, and that was really interesting. I learned a lot.

Breslin: That's wonderful stuff.

Jones: I applied to Peace Corps, and I was denied on the basis of my disability.

Breslin: Explicitly denied?

Jones: Yes. So that was unfortunate.

Breslin: You graduated in '74?

Jones: Kind of. I mean, I walked through graduation in '74, but I was missing a class because one of my minor classes didn't count as a religion class or whatever. I can't remember how it went. So then I had to go back and take another religion class. You have to understand that at UCSD there aren't any religion classes hardly. But I took the philosophy of religion, the sociology of religion, anthropology of religion, anything they offered. I packaged them together and got a minor in religious studies.

The last class I had to take--because my other class didn't count--was an anthropology class taught by an Indian--from India --Obesekera--and it was a class of only like fifteen people. It was a seminar. It was on spirit possession. It was the best class I ever had. It was powerful because I came to understand my religion differently. The way I understood my religion was we always talked so freely about the Holy Spirit but we really don't know what we're talking about. We're talking about something very powerful. We're asking for the spirit of God to possess us. When I took that class it really opened my eyes to what a powerful thing we were talking about. I did my paper on the prophet Jeremiah--the prophets are basically spirit-possessed. You think of spirit possession of black like in voodoo, but you also have the positive spirits--in this case your prophets are literally possessed. So that was a very eye-opening class. One of the best classes I had.

Breslin: And serendipitous too, that you actually took it.

Jones: Yes. I never would have taken it if I hadn't had to.

I actually got my diploma in '76. In '74 I thought I graduated but I didn't really graduate. Just before graduation I had been invited to this presiding bishop's installation in Washington, D.C. You have to understand: most people are not invited to that. The cathedral in Washington only holds x number of people. But they wanted youth representation. The only way to get youth there--because everybody in positions of power that had to be invited are old people--was to specifically invite us.

I was invited to be on the executive council for a day. It's like the general convention in between conventions. I'm not sure how many people, thirty or fifteen or whatever it is, are on executive council. So I was part of the executive council for a

day. It was funny because there were three of us and we were walking with the executive council because that's what our badge said, and people on the executive council were wondering, "Who are these people?" [chuckles]

I sat across from John Walker, the black bishop of Washington. He's dead now. I sat through the last service that John Hines would preside at. John Hines was, I would say, the great liberal bishop of the Episcopal church. He was the one that carried the church through all of the Watts and civil rights. He kept moving the church forward through all the civil unrest in a very compassionate way. It was very powerful when they read--at his last service as the official presiding bishop--about the Good Shepherd who gives his life for his flock. In a lot of ways John Hines had done that. He really sacrificed a lot of himself for the position that he had. It was very powerful.

Then the next day, John Allen, who was very conservative, took the reins of the Episcopal Church. As I went out of the service they were having this festival reception celebration. It was all balloons and circus calliopes and stuff on the lawn. I just went out the back and down the side. I was going to meet some people because we were going to talk about how the Episcopal Women's Caucus had a position opening. I was going to meet them and do an interview since I was in Washington. On the back lawn I'm seeing John Hines come out the back door with his satchel. I thought, "Oh my God, that's John Hines." I went up to him and he said, "Hi, I'm John Hines. Who are you?" It was such a humble thing. Everybody there knew who John Hines was. It was a real humbling experience of how he was dealing with the people.

West Coast Coordinator for Episcopal Women's Caucus, 1974

Jones: Then I went across the street and interviewed for a job which was the West Coast coordinator for the Episcopal Women's Caucus.

I went back to graduate--well, I thought I was graduated but I really wasn't--and I took a position of organizing around the western third of the U.S. I did that on the Greyhound bus a lot.

Breslin: You were hired for this job.

Jones: Yes. It was basically a voluntary paid position of organizing. We worked in all the dioceses trying to get people to understand women's ordination to the priesthood. The problem with women's ordination to the priesthood is if someone's never met a woman

priest--which they couldn't because they weren't ordained yet--they don't understand that it's okay. So what we were really trying to do was enable people to understand that it was okay. There was nothing earth shattering about this. So I had all the scriptural stuff on why women should be ordained, and we heard all the arguments about why they shouldn't. I knew all the arguments of both positions, and basically what I was doing was supporting the people--primarily women--in each of the dioceses of the western third of the U.S., which went as far as Utah, to create little cluster groups that could carry on the work of being a presence in their diocese. That was my work for about a year and a half.

No more had I taken the position (July 1), than on July 29, 1974, the Philadelphia Eleven, which was eleven women, became ordained to the priesthood irregularly. What happened was these women were all very top of their field. It was a sacrificial act because they knew if they proceeded with this they may never have their priesthoods regularized, they may never be accepted in the church. But they knew that if they didn't push this forward it was never going to happen, because it had been denied in '73 at the Louisville convention. The next time it would be up for election or vote would be '76. The church is very conservative, and the way they count the ballots is very conservative. If it's a tie it counts for no. So each diocese--and there are only four delegates in each diocese so the chances for a tie is very high. So these women said, "It may be forever before we get this through." So they found four retired bishops who believed that women should be ordained to the priesthood. The four bishops organized this thing, and they sat around one night and figured out when to do it. July 29 is Mary and Martha Day, so in Philadelphia eleven women were ordained. Then shit hit the fan.

What happens is the men close ranks. We all know that. It's called collegiality of the house of bishops. The bishops didn't want to reprimand any of the bishops for ordaining women to the priesthood, because, "if the Spirit has called you to do this"--you know, all those arguments. So they had a meeting of the house of bishops in Chicago that summer, the summer of '74, and I flew in to watch it. We couldn't go on the floor because just the bishops were allowed on the floor.

Breslin: Just the guys.

Jones: Just the guys--100 percent guys. Except that when they have Eucharist everybody's welcome at the Lord's Table. So when they have Eucharist in the house of bishops, everybody is welcome on the floor to partake. It was really interesting. We all understood the dynamics of what was going on there. Yet in the

meantime all of us kind of stood around the outside watching this thing go on. In the end they didn't want to censure their brother bishops, so they let the irregular ordinations of these eleven women stand.

Breslin: In this case "sister bishops," right?

Jones: What?

Breslin: The women who had been ordained.

Jones: The women were ordained priests. Bishop is the next level up. Women bishops wouldn't happen for another fifteen years--1989 in Boston, Massachusetts.

Breslin: They weren't bishops.

Jones: No, no bishops. Male bishops. But see, the brother bishops didn't want to censure their own male bishops who had ordained the eleven women to the priesthood, and so what happened was they let stand what had happened. Later the eleven women were regularized. When I got home from Chicago I was talking to a friend who was in the women's ordination movement, and I was telling her what was going on and I didn't get back to my house right away. I was staying at my parents' house that summer. I really wasn't there much, but my stuff was there. A friend from college was there that weekend. She had come down for the weekend to go to the zoo or whatever. I told her she was welcome to stay at our house but I'm not going to be there much. She waited until I got home, and we had a couple of hours before she went back to L.A. That weekend she was killed in a boating accident. I hadn't seen her in two years. I thought, "Whoa. You've got to watch how you spend your time." It's not disability, it's just "stuff."

Women were ordained. It got passed. Pretty amazing, isn't it?

Breslin: Big stuff.

Jones: That was big stuff.

Breslin: That was a very important moment.

Jones: In the meantime I went to my bishop and told him I felt called to the priesthood.

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Jones: So Bishop Wolterstorff, after this discussion, said, "Well, you're short, overweight, disabled, and female." Those were his exact words. I went home and I cried. I cried not for me; I cried because that's the basis on which he was making ordination decisions, and that was awful. It was awful. To think that the diocese was calling people on the basis of whether they were male, nondisabled, thin, and tall. None of those are characteristics which have to do with the calling. I felt sad. I don't think he really even realized what he had said.

Breslin: It would make you challenge your faith in that system anyway.

Jones: Right.

We were pretty much on the way with canon law change, and things were happening, and the caucus project ended in September '75. I was taking a little while off. I was at liberty, shall we say, partly because I was a little burned out and partly because mainly I needed some time.

Then I started looking for a job. It's hard getting a job when you're disabled. I put in some résumés at places and I wasn't really called back.

Breslin: What were you thinking about in terms of work at this point?

Jones: I thought I could do some coordinator or advocacy kind of work.

Breslin: Science was not on the agenda.

Jones: No.

Breslin: How come?

Jones: I don't know. It just wasn't. Between my junior and senior year, '72 and '73, I actually worked for a summer at the UCSD hospital. I was doing bloodwork. I wasn't drawing blood, but I was involved in spinning it down and doing some stuff in the rheumatology lab. I thought, "God, I don't want to do this the rest of my life." What I realized later was that if I had been a little more proactive I could have gotten involved in some of the research stuff that was going on there during that summer, but no one really encouraged me to do that. Because they were basically using me as free labor they used me wherever they needed me. I wasn't aggressive or forceful enough to do some of the other stuff. The last day they said, "Oh, you could have come down here and blah blah blah." I thought, "Why didn't you tell me that three months ago?" I decided this isn't something I want to do. It was pretty unexciting.

After that class I did take immunology. I took a class on the lactose operon and all of that crap. Genetics. The stupid genetics class. Fruit flies, fruit flies. I took fruit flies home with me on Thanksgiving weekend because I didn't want them to get killed over the weekend when I was not there. You have to babysit your flies and all that stuff.

It was time to do something else. I really enjoyed doing the caucus work. That was when I had this motto: You have to act them into a new way of thinking because you cannot think them into a new way of acting. Once people met a woman called to the priesthood, they could not deny that this was real. So one of my strategies had become to create events around the western third of the United States where we brought women in to be introduced or to have evenings in their house. Of course, Berkeley has a lot to do with that. One of my first things when I was hired was to come to Berkeley and talk to the dean at the CDSP [Church Divinity School of the Pacific] because that was where a lot of women were in seminary. There are so many seminaries of different denominations there. The guy, I think it was Julian Bartlett, this was before I actually got the job; he was confirming that I would get it. He said--this was just before I started working for the caucus--"If you get this job it's opening a can of worms. You'll never look at the church the same," because it's all church politics. I said, "Yeah, I guess," naive that I was, but that's what I knew and you can never see it the same.

Breslin: He was right.

Jones: He was right. You'll never see it the same. It's actually good because I see the church for what it is: it's an institution. It has very little to do with God. I don't know how else to say it. I mean, it carries on the faith, but sometimes the faith carries on the church. At this point in my life I'm very discouraged with the church, but we'll get on with that later.

Breslin: Let me ask you a little different question about this transition period here where you're starting to look for work and you're thinking and rethinking and moving into being an adult. Did you have any perception of a disability movement or anything going on in the disability area at this time?

Jones: Not really. There had been some meetings. Jim Hammitt and Larry Adams had met with Dick [Richard] Wooten, I guess, and they were forming what became CAPH: the California Association of the Physically Handicapped, which later became Californians for Disability Rights. That was going on, and I was at one of the

early meetings in San Diego which was the first chapter of CAPH. I was at one of those first meetings.

It was interesting because all the students from Sunshine--the Sunshine alumni--had to vote to turn over their files to CAPH. Sunshine alumni became CAPH's chapter in San Diego. How's that?

Joining Mainstream Magazine, 1976

Breslin: Small world.

Jones: Small world. That was the beginning in maybe '72 or so. I can't remember when exactly it was. I put in some résumés and I hadn't gotten a job, and I kind of wasn't too concerned about it because I wasn't really confident of what I was going to be doing. Then Larry Adams from Sunshine School calls me up and says, "You're not doing anything right now. Why don't you come and help get this magazine started?" I said, "Okay, I'll come down and talk to you."

So I went down and interviewed with Jim Hammitt, who had cerebral palsy, and Frank McGovern, who was not disabled but was a journalist and was going to help do this thing. I interviewed and got a job as one of the disabled trainees of Mainstream magazine the first year. We started in January of '76--I interviewed in late December '75 and got the job and started in '76. It was twenty hours a week at minimum wage. The trainees came in, there were twenty-eight or twenty-nine people. They were mostly people who were disabled and who had gone to college and couldn't get jobs. It wasn't people who were uneducated. There were people who had completed four-year educations at San Diego State. I had gone to UCSD; someone else had gone to Cal Western. It was quality schools.

Breslin: Tell me who conceptualized the program and who funded it and what its purpose was.

Jones: Jim Hammitt conceptualized the program because he had cerebral palsy and had a speech impediment, and he knew that the community needed a voice. He thought the disabled community needed a voice, and he thought to create a vehicle that would give the community a voice. That was the idea. Then they had to get it funded. The first two Mainstreams were really four-page newsletters--fold-over type of things--just two pages folded in half. Then they applied to get RETC funding, which is Regional

Employment Training Consortium money. Mainstream was funded--oh gosh, this is so crazy. I think it was \$100,000 a year, which is nothing now. You'd think, "Oh, my God, you can't do anything."

On that money they funded the printing and mailing of the magazine and half-time staff positions for twenty-eight people or whatever it worked out to be. Frank McGovern was the full-time paid person. I even think Jim was a part-time paid person; I don't think he was full-time staff. I think Frank was the only full-time staff person on the payroll, although I may be wrong. They rented this office space in downtown San Diego. They rented there because the buses stopped downtown and people could get there. Pretty logical. Public transit. There were not curbs cuts, and that was an issue, so one of the first things we did was talk about the lack of curbs cuts in San Diego. People couldn't get down the street, get off the block.

I started working in the production department, doing page layout stuff and typesetting. I can't type for nothing; it's hard. We didn't have one of these new desktop publishing things; we had what was called a compugraphic. It was one of these things where you had to type a line. A line in typeset is only thirty-four characters, plus or minus. So you type this line of thirty-four characters and then you have to set this dial and then type it exactly the same way a second time. So you have the first column of type, which is all ragged. Then you get the real set of type, which is justified type. That was a very hard process, to get the type set. Then we had to spray fixative on this stuff so it wouldn't smudge, because this was like carbon ribbon on paper.

Breslin: Like the early photocopy kind of things?

Jones: It would be like carbon paper. You know, the carbon ribbons. So if you touched this copy it would smudge. What we did was we sprayed hair spray on this copy [chuckles], and you had to be very talented at this task, because if you sprayed too much it would run. Heaven forbid if you ruin a column of set type. So this is how we did it, and we were getting a little behind because nobody had such great typing skills to do this task, which was very tedious.

Then this one guy came into the program, thank God. God sent us Jonathan Lee.

Breslin: The typist [laughter].

Jones: The typist. Jonathan Lee was just out of the navy. I'm not sure what his disability was, but it had to do with a collapsed lung

and complications thereof. I'm not exactly sure, but he had a significant breathing disability, that his lung would collapse occasionally, which was critical. He had actually been in the navy. His job in the navy was radioman, so he knew how to type. He had to know how to type accurately and fast. That was a blessing to us, and thank God for Jonathan Lee, because he got us through.

One of the first issues we did was on transportation. These are all basic issues. They're still the same issues today. Curb cuts and public transportation. We were there and we were getting giddy because it was very late one night, and we had to come up with a headline for this transit story. It was on paratransit. We were sitting there thinking, thinking, thinking, and finally--I don't remember who came up with it--but we said the headline should be called "Dial-a-Wait." [laughs] We didn't use that, but all of us remember thinking that headline.

Those headlines had to be pressed set. We had a whole set of alphabet things, and you had to press it without breaking it because again it was carbon. We didn't have any of the high-tech stuff. This was really loving hands at home.

So we got the first issue out, and we were there all night. But we never missed a deadline; we were always on time and the printer was always happy that we were there when we said we'd be there.

I was pretty good at getting stuff done and organizing, so I would run the production crew and I did other stuff. I did fundraising and anything that basically needed to be done.

Breslin: Who was the magazine going to at that time?

Jones: It was going to people in San Diego. I think the first press run was 5,000, and then it went to 10,000. It was going to different organizations in town plus any individuals that had sent in their name. I can't remember what the first original price was--three dollars a year or something. It was very marginal.

Breslin: You built a mailing list from whatever.

Jones: From nothing. From scratch. It was black and white, there was no color. It was glossy. It began on a glossy stock. It looked good. We had professional photos. Carol Vincelett, who I knew from Sunshine School--she was my best friend--she had graduated from San Diego State with her teaching credential but she couldn't get a job because people wouldn't hire disabled

teachers. She was an artist as well, so she did a lot of our drawings and stuff. That was a lot of fun.

Work Experience Program

Jones: At the end of the first year they had a job counselor come in--that was part of the grant--and she helped everybody get their résumés together and do job interviews. She did training on how to do an interview. Some of the people she actually went with on the interview. She really worked to find places for them to interview. She did her job well. The people at the end of the first year wound up getting a real job. A couple people wound up getting jobs at San Diego Gas and Electric. One of the women was in the graphics department; she had been in our production department and she got a job in San Diego Gas and Electric's graphics department. She was there for a long time. She might still be there, I don't know. Another guy wound up being in their accounting department as like their bookkeeper person. Another guy, Rich Watkins, wound up getting a job as a teller at San Diego Trust and Savings. When they got bought by some other bank he was a vice president. He is now a vice president of Union Bank of California in their commercial loan department.

People got real jobs out of this. It wasn't just overnight. Carol Vincelett wound up getting a job in a program called Search and Serve, which was to find disabled students. After that, she wound up getting a job in the Lakeside School District in junior high. She's there today. I think she's been there like twenty-something years. She got that job as a result of being at Mainstream. It was a tremendous opportunity.

Part of the gift of Mainstream in its early years was that it was a nine-month program--nine months of working in the program--

Breslin: Kind of OJT [on-the-job training]?

Jones: Not OJT. It was called Work Experience. What that meant was people came in and had a job for nine months. Although it was half-time they still had to be there every day, they had to get up and get there. All the stuff of being at work every day. They got a paycheck. Then at the end of the nine months they started phasing people out and helping them find jobs. So they had like three months left to help them find jobs. But the important part of the nine months, really, is that it was a birthing process. It really was a birthing process. Now I know

why birth takes nine months. It was a change of attitude. A lot of what happened in the course of people working there nine months was just the camaraderie and talking about issues that people don't have a chance to talk about. Working through things that people never have someone else to talk to about these things, whatever it is. So it was a really wonderful kind of experience.

The first year, I was training and I should have gotten a job but they couldn't get rid of me because I wouldn't go. They needed me. The program needed me. They offered me a job full-time, low pay, for the second year. I was working sixty-hour weeks. We were working really hard keeping this thing up. Then it got a little bit easier, and it got on a regular cycle. I took a few days off and I couldn't go back. I mean, I came back and I gave notice. I realized I had been working sixty-hour weeks for like two and a half years. I was exhausted. It's like until you stop you don't realize you're tired. Once I did I couldn't do it again. I couldn't crank it up. I was only twenty-three or twenty-four [laughs].

White House Conference on Handicapped Individuals, 1977

Jones: I went back and gave them two months' notice. I figured that was enough notice. If they can't find someone to replace me in two months, too bad. That's enough time. Lo and behold, what was at the end of that was the White House Conference on Handicapped Individuals from Washington, D.C. That was like my last thing. I went with Jim Hammitt, who was the editor of Mainstream, and that was my last task of Mainstream.

Breslin: This was in--

Jones: May of '77. Let's think about what was happening in May of '77. Think back a couple months. This is really funny. Actually, whoever timed this did great. Of course in April were the 504 sit-ins. People were sitting in up in San Francisco, and they're going back to Washington, and they're negotiating with [Secretary of Health, Education and Welfare Joseph] Califano to sign the 504 regulations. All this is going on.

In the outside world what's happening? Thousands of people with disabilities are going to converge on Washington, D.C., so they had better sign those regulations [chuckles]. You can kind of see their mind working that they have this huge army coming in on them, that they had better get this negotiated before this

army comes. If thirty who went to Washington were making such a ruckus, several thousand could make more of a ruckus. I know that must have been playing in their heads. You know that they knew that everybody was coming in a month. Maybe, maybe not. But I like to give them the benefit of the doubt.

Breslin: I liked the image.

Jones: The image is good, isn't it? I like the image.

Breslin: Were you guys at Mainstream aware of what was going on with the regulations?

Jones: Yes, we were. I wasn't involved in the sit-ins. I don't know if I've never been really an activist. I'm an activist, but I never think about getting arrested. I never think about that kind of stuff. I guess I think somebody has to be working on the outside getting the job done too. Maybe that's a cop-out, I don't know. At some point I might be called to be on the sit-in, but up until now it's not been my role.

Breslin: Did Mainstream run any articles about the proposed regulations?

Jones: No, they ran articles about the sit-ins.

Breslin: Not about the issues involving--

Jones: I'd have to go back and look.

Breslin: Because the issues were cooking well over a year before the sit-ins.

Jones: Yes. I'll have to go back and look and see what was in there.

A lot of stuff that was going on at Mainstream at the time was local. It was a local magazine. Ed Roberts did come and visit, and that was important. He was impressive.

Breslin: In what capacity was he there?

Jones: I think he was the director of Vocational Rehabilitation. He came down because we were a voc rehab project. I guess we had been funded as a three-year demonstration project.

Breslin: So this Regional Employment Development--

Jones: They funded part of it and then voc rehab funded the rest of it. So I guess the funding--I'd have to go back and look. I probably

can't even go back and look. It must have been like \$130,000. Still, if you think about it, that's not a lot of money.

I went to Washington. That was a mess. The elevators [laughs].

Breslin: That's the first one of those you'd been to, right?

Jones: Yes. The elevators. The lines at the elevators were a mile long! If you had to get anywhere you couldn't get there. You had to be where you needed to be or you were out of luck. We took over all the freight elevators, the service elevators. It was a mess. Even then, all these people in power chairs had too long of days and too short of nights and their batteries didn't have time to charge, so they were running extension cords all over the hotels during the meetings because they had to charge while they sat and talked. The logistics were a nightmare. I remember, because I was still a walkie, that it was politically incorrect to try to squeeze into an elevator. You wait your turn in line with everybody else. That was what I thought. There might be twenty people in line who are in wheelchairs, and two of them could get on, and then what you'd see is a lot of walkies get on the elevator. That wasn't fair. So there was this kind of tension and dynamics going on about what was fair.

Breslin: Elevator protocol.

Jones: Elevator protocol. When we got there, Jim and I--by the way, that was the first time Jim had flown on an airplane. Of course, I was a seasoned traveler by now. We were staying at my friend's house. I had friends in Washington from the caucus days. We were staying at a priest's house. I was sleeping in the living room and Jim was sleeping upstairs because I didn't do stairs very well and he did stairs fine. He was in one of the bedrooms and I was down in the living room and that's how we went to the White House conference. We were not delegates; we were press. We were covering it for the magazine.

We get there, and we're on a real tight budget. Mainstream has always been on a tight budget. The delegates got this packet of tickets for all the meals and all the arrangements, but we didn't get that because we weren't delegates. To pay for that was a couple hundred dollars. I can't remember exactly, but it was a lot of money. We thought that we really didn't need to eat that much, so let's just think what we really need to do. We were buying food as it was, and we were packing lunches from the priest's house.

Then the next day I went into the civil rights workshop and there was this guy sitting there in a wheelchair, and there was a seat on the other side of this guy. There was elevator protocol, and does that mean there's also seat protocol? Is it polite to take the inside seat when he couldn't have moved over because the chair--inaccessibility, et cetera. So I asked him if I could take that chair, and he said, "Of course. I'm not using it."

We were sitting there listening to the Californians, whether it was Ed Roberts or whether it was Judy Heumann talking about the civil rights stuff. There was a lot of hostility in the room because all the people who were non-Californians thought, "These Californians. They're so ahead of everybody else. What the hell are they talking about anyway?" It was the real dynamic of how nobody else was anywhere near where California was, and why should they be leading--I mean, it was just oddball dynamics. Of course they should have been leading the discussion; they were there to tell everybody else how to do it. But the other people were kind of offended.

Meeting William Stothers and Marriage, 1977

Jones: We're sitting there listening and this guy turns to me and says, "Do you want to go have a drink?" I said, "Yes, this is pretty boring. I don't know if they're going to get anywhere on this conversation." It turned out it was Bill [William] Stothers. We went to the bar. I don't drink, but he did. We were "meeting," shall we say, and--

Breslin: The rest is history.

Jones: The rest is history. Except for one tiny thing. He invited me out the next night to go on a dinner cruise on the Potomac. I said, "Yes, that'll be fine." Of course I was looking for any free meal I could get because we were on the cheap [chuckles]. Then I looked over and someone had left their ticket book next to me on the bench.

Breslin: Serendipity! [laughter]

Jones: I said, "Oh, I should go turn this in," being the person I am. He said, "Are you kidding? Whoever lost it is just going to go and say 'Oh, I lost my ticket book' and they're going to give them another set of tickets." Which is probably true. So what happened was Jim and I split the tickets. We figured out if we were going to eat dinner or lunch and we would divide the tickets

up for the rest of the week. The next night I went out for dinner on the Potomac with Bill. He, by the way, was staying at the Hay Adams. He was there as a representative from the mayor's task force from Toronto. So he was an international guest. So he was staying on the mayor's budget at the Hay Adams. So he was doing pretty darn good.

The funny thing was that I wasn't sure if I recognized Bill the next night. There were so many people in wheelchairs. It's not like you can say, "Oh, the guy in the wheelchair," because everybody was in a wheelchair. So I was really nervous--would I even recognize this guy if I saw him? [laughs] That turned out not to be a problem, but it did cross my mind.

Then on Friday the conference was over, and he asked me if I wanted to go to the Smithsonian. We went to see the [Air and] Space Museum. Then he asked if I'd like to go to Toronto with him. I said, "No, I think I've got to go home." I had my ticket to go home but I thought, What if I really like this guy? Those were the days before you had to pay a lot of money if you changed your ticket. I changed my ticket and I flew up to Toronto, which was close to Washington, D.C. A lot closer than San Diego was to Toronto.

I can't believe I did this. I made my way on the subway from the Toronto airport to downtown Toronto to his house on a bus. I walked half a block. I got there, and I had his neighbor's phone number and they let me into his house. So I got there before he did because he was driving from Washington. That afternoon he arrived and I was in his living room. His living room was the only place I could find that I could sit because his house was being renovated for a wheelchair. There was not even a place to wash your hair in the place, and I was so grungy. That was my introduction to Toronto.

I stayed for three days, he wine and dined me, I went home. Then he called me and said, [in a pleading voice] "Why don't you come back? Come on back!" I thought that was right, so I flew back after trying to save money by not coming home first. So I flew back to Toronto the next week and then we got married in December.

Breslin: Six months later.

Jones: Yes. He kept saying, "Do you want to get married?" I said, "You're too old." He's twelve years older than me. Actually, eleven. I was twenty-six, he was thirty-seven. Then, I don't know, we just got married. He seems a lot younger [laughs].

Breslin: So you went back to San Diego for a week and then went back for--

Jones: Six months.

Breslin: You lived in Toronto for six months.

Jones: I did. Actually, I lived in Toronto for almost a year. I was there as an undocumented alien. I just crossed the border. I couldn't work because I was undocumented. I did some volunteer work for the YMCA for women who were trying to transition back to work. I did some math tutoring.

I flew back there in June. In September he had like seven weeks vacation accumulated at the Toronto Star, so we came to San Diego and were working our way up the coast because he was going to interview for jobs all the way up the coast. He was going to meet my family. We actually rented a van. It was 1977. We rented an accessible van in San Diego and drove up the coast to Vancouver, where his family had moved to. His sister and his mom and dad had lived there. He didn't apply at the San Diego Union for a job because I said, "This diocese is too conservative. We're not going to take a job in San Diego. We're not going to interview here."

Breslin: Because you didn't want to live in San Diego.

Jones: No. The Episcopal diocese was too conservative in San Diego. We were going to go someplace like San Francisco or Portland or Washington. Anyplace but San Diego.

Breslin: He was fine about leaving Toronto and looking for work?

Jones: Yes. I often say that I accuse him of going to the White House conference looking for a southern California name badge [laughter]. Any place but the cold hole! Actually, he loves Toronto. But it was getting very hard with the snow, which was getting deeper every year. It was getting harder.

Breslin: Say something about his work there. He was a journalist?

Jones: He's a journalist. He was assistant city editor at the Toronto Star, which is the largest newspaper in Canada. It's equivalent to the New York Times. He had worked there for ten years. I don't know how much of that story you want.

Breslin: Just the context, that's good.

Jones: We were in San Diego and we were driving up the coast, and he applied at the L.A. Times, he applied at the San Jose Mercury

News, he applied at the San Francisco Chronicle, he applied at the Portland Oregonian, he applied at the Seattle Post Intelligencer. He didn't get a job [chuckles].

Then a friend of ours said, "You have your résumé ready, right? Why don't you just send it in to the Union?" I said, "Hell, you've got a twenty-two-cent stamp. Why don't you just send it in?" He got a job at the San Diego Union. So I figured that's my Jonah in the whale experience. God was sending me back to San Diego. So we landed in San Diego, and he was hired there.

It was funny. Jerry Warren, who was the editor of the Union, was supposed to come out in December in Toronto to do an interview. But there was the biggest blizzard of like the decade, and he got snowed in in Buffalo. He couldn't come across to Toronto. I thought, "Oh, my God, we're never going to get out of here. There goes our hope of ever leaving Toronto." [chuckles] But instead what happened was they flew us down in February. Going from February in Toronto to February in San Diego, I never appreciated San Diego as much as I did--even though I had lived there all my life mostly--as I did when I came back from that winter. It was wonderful. Bill got a job. They sent him to the doctor to have a physical, and the funny part was the doctor said, "Have you ever worked before?" That was the physical. "Have you ever worked before?"

Real Estate Licensing Exam and Finding Accessible Housing

Jones: So Bill started working at the Union, I closed up the house in Toronto, and I came down a month later. I started looking for a house for us. His house in Toronto had not sold yet. It didn't sell for a year, actually. I started looking for a house for us but there wasn't anybody who could really do accessibility housing. No one knew what an accessible house was. After several months of looking unsuccessfully, I said, "Hell, I can do this better." So I read a book, I paid my ten dollars to take my California real estate exam, I passed the exam--which most people think is pretty incredible--but you do it and take your chances, right? So I did. I got my key, which meant I could go into any house that had a lock box and check it out. That's how I found our house. I looked at lots and lots and lots of houses.

Our house is an old craftsman's house. It has a fireplace and built-in bookcases and a bay window seat and a china hutch. It's very nice. It has a four-foot-wide hallway, which is nice. It has an eight-foot square bathroom that you can turn around in

it and the sink and toilet work. It has a claw-foot tub. The house has three steps in front. When I told Bill to come and look at this house he said, "Is it accessible?" I said, "No, you have to have someone carry you in, so bring someone with you," because he was working at the paper. He had this friend bring him over, and he gets in the house, and it really is a very accessible house. The bedrooms are like twelve-foot square. It works. The kitchen worked. All we really had to do to really get in was to build a ramp, and that's what we did. Once you get on to the front porch, which is about five or six feet wide, there is a level entrance. So all we had to do was ramp the side. We didn't ramp the front of the house because we didn't want it to look like a cripple house. We didn't want someone from the street knowing that this was a house that disabled people lived in, and we also didn't want to deface the front of our property. So we did it more--I don't know if gracefully is the word.

Breslin: It's up your driveway.

Jones: It's up my driveway. You're dead, I'm tired.

Breslin: I just want to ask one last question: this was before or after you were married?

Jones: We were married in Toronto on December 21, 1977. That's a civil marriage.

Breslin: This was before the February jaunt back to San Diego.

Jones: Yes. Then we had our church marriage in June of '78. So we have anniversaries twice a year, every six months. It's very confusing but kind of nice because it's never too far to an anniversary [laughs].

Breslin: That's a nice way of looking at it. How was your family about it? And his family?

Jones: Oh, they were fine. It was very nice. It worked out really well.

Breslin: Everybody met everybody.

Jones: Yes.

Breslin: You were talking about the house but I was trying to figure out when the marriage was, related to--

Jones: December '77. We got married in Toronto. He got offered a job at the UT [Union Tribune], but to come into the United States he had to get a green card. So he had to go to the American Embassy in Toronto. He filled out the paperwork and we were married, and that's fine and you can bring in your husband when you're married. All this is fine, except that the American Embassy in Toronto is inaccessible. So he was fingerprinted in the back of our van. I think that's kind of fun. All of that turned out to be unnecessary because Bill was actually born in Detroit. He became a naturalized citizen in Canada, but the countries don't tell each other about who becomes naturalized, so all he would have had to do was cross the border and say he was born in Detroit, Michigan, which was the truth, and no one would have known that he had become a Canadian citizen.

Breslin: You just become an American citizen again.

Jones: Right. He could have just said, "Oh, I was out of the country for twenty years," which was the case, or thirty years or whatever it was. He could have just gotten his Social Security card. The question would have been, Why don't you have a Social Security card? "Because I was taken to Canada when I was a child by my parents." At any rate, that didn't happen that way. He went through all the immigration stuff, and he actually became a naturalized citizen about two years ago on Flag Day. So he was naturalized back as an American citizen.

We had our church marriage in San Diego in June '78, and we bought our house February '79. That's the timeline. So we've been in our house twenty years now. We've been married a long time. It's actually kind of a "happily ever after" kind of story.

II RELATIONSHIP WITH MAINSTREAM MAGAZINE AND GROWTH WITHIN THE DISABILITY CIVIL RIGHTS MOVEMENT

[Interview 2: March 14, 1999] ##

Practicing Real Estate in San Diego

Breslin: We ended last time about 1978. You had gotten your real estate license and had bought a house in San Diego and were ready for the next phase. What happened then?

Jones: I was doing real estate. I sold a number of--I wouldn't say they were adapted houses, but I would say they were easily adaptable houses. I had a really good sense of what was an easy-to-adapt house. Not like what most real estate agents think, "Oh, you can just tear out the kitchen and redo the bath and add another room on the back." I was able to really find some wonderful houses for people where they had to do a minimum of accommodations to get it done. That was really satisfying. It was really a service industry. You got to know the people and what their needs were. It sounds funny but if they were left-handed or right-handed; a lot of that stuff makes a difference when you're getting your home ready. I was really good at finding the little things that made it work for people.

In the meantime, Able Disabled Advocacy--which was the parent organization of Mainstream magazine--had asked me to be on their board of directors. I did, and that was like a loose commitment once a month. It wasn't a big deal.

Then a couple things happened. There was a recession at the beginning of the eighties, and the company I was working for went out of business, so then I went over to another real estate firm. It was kind of in an upscale neighborhood of San Diego, although I was usually selling downscale houses [chuckles]. But I was selling a lot of houses. In fact, the year before that--before this one company went out of business--I was the top sales agent in San Diego county. That goes back to my peanut sales days. I

was really good at what I did. During that time I did executive relocation for all of Citicorp into San Diego. I did six of their top executives. This wasn't disabled stuff; this was just because I provided really good service. I provided good service --this comes back to what do people with disabilities have to offer--I provided good service because all of my disabled clients needed really good service. They couldn't have "this kind of works" or "this kind of meets your needs." I was really tuned in to what someone needed, and provided the best that we could find.

It was really good to do this. The executives are all men, and the spouses are all women. The man is moving to a promotion and the woman is leaving her life behind and coming from the Midwest somewhere where she has a 3700-square-foot house on two acres and coming to a 1200-square-foot house in San Diego. Really shocking, shocking stuff. The house prices in San Diego were so high that the women were really giving up a lot to come. It was kind of a ministry in a way, because you had to kind of help these people find new friends in the neighborhood and introduce them. Mainly give them a grounding. I remember one woman--we had been looking at houses all day--we stopped for a late lunch and she just started to cry. She was just in tears that this was what this was going to be like. It was really hard handling some of that stuff. But we got through. We sold her a house, moved her in, things were better.

Breslin: This too will pass.

Jones: This too will pass. I did some stuff like when people were coming in from St. Louis, they were moving in, and I would call the gas and electric company and get their gas turned on and their phones established. Sometimes I just made up maiden names because you have to give them your name to set up an account. So I'd just give the people the name I used [chuckles]. Because if you fly in on a Friday night and you don't have lights until Monday, it's hard. These were just what I called "service items": making it nice for them to come in.

As a result of that, one sale led to another and another, and pretty soon I was the top sales agent in Walker and Lee, San Diego county.

Breslin: Great customer service. I hope they appreciated you.

Jones: Yes. It was nice. It felt good. One of the guys, I sold him moving in, and then I sold him when they relocated him to another position out. So I got both ends of the transaction from him. It was a real positive time in my life.

Then that real estate company closed down because of the recession. The recession meant that in California, specifically in San Diego, you couldn't assume someone's mortgage. It was due on sale.

Breslin: Mortgages were assumable or not, and they became less so as time went on in those days.

Jones: Right. And the banks were calling the notes due on sale.

Breslin: Making them refinance.

Jones: But what was happening was that the rates were skyrocketing. They were in the high teens. Mortgages were like 17 or 18 percent. People couldn't afford to buy a house at 18 percent. The mortgage that was on the house would be like 9 or 10 percent. What people were doing was creative financing. Creative financing meant you opened an escrow account, you put the money in escrow, and then you leased the house for years and years. It never really changed ownership until some date in the future when the person wanted to refinance when the rates came down. That sounds okay--sure, you're able to lease out your house, that's legal. But the way this was done was really a circumvention of the mortgage conditions. So anyone who was doing this--I did this for a couple of clients--I wasn't at risk because the client signed papers and knew that they were doing this.

But if the mortgage became due on sale, if the note got called, the client had to be able to perform. They had to be able to refinance and qualify at the higher rate; there's where the risk comes in because if a client isn't able to qualify at 18 or 16 percent or whatever the current rate was, then they could actually lose their house because the house would be foreclosed on. So there was, in my mind, a very risky piece in that. I was really uncomfortable. I did this for a couple of clients because they really wanted it done and they were fully aware of the risk. I couldn't have that be my regular diet. I was very uncomfortable putting people at risk. You can only put your clients in as much risk as you're able to assume yourself. They may be fine doing all that stuff, but if I'm uncomfortable I can't make the transaction happen. I was always a buyer's agent; I could never do a sale on the other end. I couldn't sell a house, but I could buy a house for someone. I was really good at being the buyer's agent; I loved doing that. That part was real good.

So the mortgage rates were high, we were having to do creative financing to close houses, a lot of crazy stuff was happening in the real estate market. One of the things was that

people would come in like on a street sign or an ad in the paper and you would show them all day and then they would buy for sale by owner, and really that was their intent all along, so they were using our time and our gas money to make sure that what they were buying was a good deal. There were a lot of days and weeks of wasted time and twenty dollars a fill-up; you start paying out all this money and you're not making money because people are trying to find a way to buy a house cheaply in a tight economic market.

There was one house, a multi-story house, that I loved. I showed that one house to more people because it was one of those special houses that might be a little more than they wanted to spend but it was worth it. It was a good deal. It really was a wonderful property. A couple came in and I showed them the house, and then they bought it through their agent that they had been working with prior. I was so pissed! I must have shown that house a dozen times, and this couple would have never found that house had it not been for me. I was angry because I had caused that sale to happen. But the listing agent was in our office and they didn't want to screw the deal, so basically I didn't make any money on it. The owner was really angry too because he knew that I had shown his property a lot and I was really trying to sell it for him. He was kind of unhappy because he knew I had caused that transaction to happen. This was all within about a year's time.

The next thing that happened was one of the agents in San Diego--not from our office--got killed in a vacant house. Her throat was slit. People don't realize how dangerous real estate is. You're taking people in your car to places that are empty with no phone service, and in those days there were no cell phones or whatever. What happened was a chill went through the real estate industry in San Diego. You were very careful about who you took in your car, you were very careful about going to an empty house and meeting someone there. In our office the policy was you could never meet anybody in an empty house. They had to come into the office and leave their driver's license. There were very clear policies after this happened for security for the agents. But even that is really not sufficient.

This one guy called up and wanted me to show him a house. Then a couple days later he wanted me to meet him at his restaurant--he was an owner of a restaurant--then show him this other property. I get to the restaurant--it was like a bar--it was noon, and it was dark because they're not open until night. Still, you're going into this place that's dark and kind of weird, and there are no lights and there's nobody there. It just kind of freaked me out because we were still thinking about this

woman that had gotten murdered. It made it so that I really couldn't establish the relationship with him so that he would trust me so that he could buy a house. There are a lot of things that go into a real estate transaction that people aren't aware of. I couldn't establish a relationship with him because I was kind of frightened.

Gays in the Episcopal Ministry

Jones: By now it was '82 and Reagan had taken over. I had been working with a friend of mine--this is going to backtrack a little bit; it goes back to the Episcopal church stuff. At the same time that we were working on women's ordination to the priesthood, we started working on acceptance of gays in the ministry as well. They were kind of like parallel routes. Women had gotten ahead mainly because they did this irregular ordination and kind of pushed the system.

I remember what they said to this woman, Carter Hayward--she's now a professor at Harvard Divinity--well, Episcopal Divinity School at Harvard. She said, "The gears in the machinery keep cranking. In order to stop the machinery someone has to throw their body into the gears." It's such a graphic image. It's kind of like what Martin Luther King did. If you're into the movement--disability rights or whatever--in order to stop the status quo from just churning forward, people have to be willing to sacrifice whatever it takes to stop the machinery.

The interesting thing about the eleven women who were ordained was that each one of them felt called to the priesthood, and they were called for a long, long time. Decades and decades. But they knew that if they didn't do something dramatic, the debate over women's ordination could go on for decades in the future. Each of them knew that by doing this irregular ordination they may never be able to act as a priest. It was really sacrificial but a lot of people out in the real world, and even in the Episcopal church, didn't understand what a sacrificial act they had done. They were willing to put everything they believed on the line to stop the machinery from going forward. I kind of backed up on that because it's a really powerful message.

At the same time there was a group in the Episcopal church called Integrity. Integrity is the gay movement in the Episcopal church. A friend of mine, his name is Cal South, had come to our church. This is backtracking a little bit, but we were getting

ready for the '76 convention, I think. Integrity wanted to have a presence at the general convention which happens every three years. I had just sold a house, and I tithe my money. I can't remember if it was \$100 off of a \$1000 sale. Maybe it was fifty dollars. Whatever it was, I donated it so they could have a presence at the general convention. It wasn't just San Diego, it was the national group.

A couple years later Cal had had a condo on the beach in San Diego, and it was a wonderful property. It was wonderful to open-house that property because you're sitting on the beach, looking out over the Pacific Ocean, hoping someone comes in and buys the property, but not really caring if they do because you're sitting there on a Sunday afternoon and it's beautiful. The property didn't sell because the market was so tight and the rates were so high. It went on and on and on. I was unhappy that I couldn't make this property sell for him.

Cal taught me a lot. One of the things he talked about was that his first partner had been in the military in Italy in World War II or just after World War II. They had been together for like twenty-five years. His partner died and Cal said, "If I was a woman I would get benefits." It was really sad. "But the military doesn't understand that we had a relationship." It's really powerful stuff. That had been a few years prior to my really knowing Cal. So now his new partner was coming out from New York. They wanted to sell this condo and buy a house, but we couldn't sell the condo; the market wasn't moving. This was maybe a year on the market. I thought, "Oh, God. What do we do?"

Finally I got off the transaction and I thought maybe he needed somebody who was just a beach property person that has more contacts with people who buy beach property. It still didn't sell for a long time. But when it did sell, it was a real interesting transaction because who bought it was a gay couple from Mexico where the money was doing real well at the time. They bought Cal and Bill's condo, and Cal and Bill bought a house from a gay couple in Claremont. So it was this wonderful kind of transaction. It just felt so right, and the house they bought was a wonderful house. I don't want to say they lived happily ever after because Cal has since died. That was very sad.

Breslin: The point that you're making, I think, is that the lessons you learned from working with gay couples and gay individuals in the Episcopal church showed you some path, ultimately, that was important for you to take.

Jones: I don't know where I'm going. There's probably some point here, and I can't remember where it was when we started this discussion.

Breslin: I think you were saying that the move to include gays in the church, and include gay issues and deal with gay concerns, was spearheaded in some ways by people who were being sacrificial or being brave and undoubtedly serving as a pivotal role model for you too on your own issues.

Jones: I think a lot of times the issues are overlapping and we don't see how they overlap. We don't understand sometimes how we're discriminated against. I think all of these ways, when you see discrimination, it informs you about how you're discriminated against. I think that's some of the issues. We were talking about real estate and the fact that when they bought that house it was a very risky transaction, and I felt very uncomfortable. In fact, that was the last real estate transaction I did. Here their condo's been on the market for a year and a half or two years--a very long time. Cal, because of his circumstances, really didn't have the ability to qualify for a house. He had the ability to buy a house but not qualify for a loan--at least not at 18 percent. So when they bought this house I was very uncomfortable because they were really at risk. I mean, if that note gets called they cannot perform. Bill had a job but he didn't qualify--together they wouldn't have qualified, and I'm not even sure whether the lender would count both of their incomes.

Breslin: This was Cal's current lover at the time.

Jones: Yes. I was really concerned. I felt uncomfortable enabling that transaction to go forward. But Cal knew full well the risk involved. We talked about it a long time. They were willing to proceed with it because they wanted this to happen. They said, "Oh, they're not going to call the note due; it will be okay." Actually that's what happened. The note wasn't called due and everything was fine, and when the rates went down they refinanced. They lived happily ever after from the real estate point of view.

But for me all these things--the murder, the funny transaction where I got ripped off out of my commission, and all this stuff going on, I thought, "I can't do this anymore."

At the same time, Reagan had taken over and Mainstream was on a work experience program and all work experience programs had become unfunded that year.

Mainstream Funding, 1982

Breslin: Let's just stop there for a second and talk about Mainstream and its purpose from the time you left to now. Was it funded in the same way, the same goals?

Jones: Yes. That's a good point. RETC, which was the Regional Employment Training Consortium--and that's how it began--the first year or two the people came in and were there for nine months. It was a work experience program, and they worked half-time at minimum wage for nine months. It was a really good program because people could kind of talk about their issues in a very congenial or peer model--things that people don't talk about--we talk about; outside they don't talk about them. In the beginning the only nondisabled person working there was Frank McGovern, I believe. He was friends with Jim, and he had helped write the original grant that got Mainstream.

Frank had since gone on, Jim had gotten married. That was a very wonderful love story. He always used public transportation. He was CP. He could walk, but he certainly could not drive. He had a severe speech impediment. He was on the bus one day, and every day he would go back and forth on the bus. I guess when you go to work at the same time you have kind of the same people on the bus. One day we got this letter in at Mainstream from a woman who wanted to know how to talk to someone with CP. She had actually had a crush on Jim on the bus, but she didn't want to offend him by doing the wrong thing. So she wrote to us and then Jim wrote back in the magazine responding to this letter to the editor on how to talk to someone with CP. He gave the protocol on it. At any rate a couple years later they wound up getting married.

Jim, who I had met at Sunshine School, had since applied to Cal State Northridge. He wound up getting his degree in communications, and he's one of the people at Cal State Northridge who does--they put on plays and--he's done really well. You think of someone who came up from Sunshine who, because he had CP and a severe speech impediment, he really was not educated. He had to teach himself to read even though he was in school. All of the horror stories we know about special education, Jim Hammitt survived special education.

At this point in 1982, in July, Jim had just left Mainstream. He was going to start at Northridge in September. Frank had moved on, and the new person that had come in--again, a nondisabled person was running the show at Able Disabled

Advocacy--was Andy Ozols, and he had come from a rehabilitation model background. The Kessler Institute, I think.

Breslin: But the training model, the funding model, was the same.

Jones: Kind of, but not really. They started turning people over first in six months, then in five months, then in four months. Pretty soon it's not the same program because you don't have the time to establish the relationships where you really get to the heart of some of the core issues that people have about working. Not just working, but being in society. That piece had gone. When you think about someone being in that program for three months, that wasn't really enough time for any real work experience to take place.

So in the summer of '82 we had a board meeting because they got notified that they were unfunded the next year. Because of Reagan they were only going to fund on-the-job training. They were no longer going to fund work experience. Well, on-the-job training, as far as I'm concerned, should have been the one that bit the dust. But see, they have good statistics, high numbers. But what is the turnover rate? It's basically get a job, get fired from the job, back on the rolls, get a job, get fired from the job. It's just a revolving door, whereas our placements were really solid. It was unfortunate. I felt really bad that that had happened.

So now Mainstream is unfunded, and they have to do something with it. Andy offered to buy the magazine. I'm on the board, and we have this meeting in a restaurant, and I thought, "I put too much energy into this to give this to this nondisabled person," basically. I'm cleaning up my words. I'm not going to let that happen! The real estate market was crashing, I wasn't comfortable with the transactions I was being forced to do. I couldn't do those transactions. I felt unethical about it, I guess. It was okay, but I couldn't do them. So the timing was right because Bill was working at the newspaper. He was making a good salary. He didn't care if I worked at real estate or what.

I was in a position that I basically said, "You can't give Andy the magazine because you have a fiduciary responsibility to the people who have donated money." I just flim-flammed this whole thing. Smoke and mirrors. I threw up all this stuff and they said, "Well, what are we going to do if we don't give it to Andy?" I said, "I'm willing to come in, and I'll volunteer for two months while you decide what to do with this magazine." That was in June. So it was set that I would start right after Labor Day. Their funding was, I guess, through October 1. I said, "I'll volunteer for two months while you make a decision. You

shouldn't make a decision in haste on this magazine. Once you start thinking about what you want, it'll give you time to make a valid decision."

So I'm closing the deal with Cal, and kind of a funny thing happened, and I did another transaction actually, which was like a ten-day transaction. I had never done a ten-day transaction! It was just like a gift; it was like cash. Here, I'll send you on your way with \$1000.

Volunteer at Mainstream for Two Years

Jones: Then I started working with Mainstream as a volunteer. At the time I took over--we'd never had money at Mainstream and we still didn't up until the end--Andy comes into the office and says, "You might as well take this call." Andy was there as the director. They had two programs: one was called Project Hired, which was on-the-job training, and it was still continued to be funded. Mainstream was defunded. So he was still the executive director of both even though now there was only one. Anyway I took the call and it was the printer saying that they couldn't print the magazine until they got money.

Breslin: The first of many similar calls [chuckles].

Jones: Yes. Then the landlord called and said, "You know, you're behind the rent." My response was the same to all these people: Look, we've had a lot of financial things going on. I've just taken over today, which was the truth, or this week. I am going through everything and you will be paid. One by one we got people paid, little by little. A miracle happened, and that was that the board had submitted for funding from one of these women's groups--

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Jones: This group--I think it was Las Petronas--they had agreed to donate \$2500 to Mainstream, and it was for a specific thing. I think it was a copier or something. But we didn't need a copier; we needed to pay our rent. We needed to pay the phone bill. We needed to pay whatever. The way these programs go is you submit the grant thing, and it's months and months later. To be honest, we forgot that we even submitted this grant. So it was like money from heaven. In fact, that's exactly what it was: pennies from heaven. I called up Las Petronas and said, "The truth is we've been defunded and what we really need to do is pay our rent

and our printer with this money if you would please allow us the opportunity to spend your donation in another way." They said, "We just want you to have the money and spend it any way you need," even though it's a designated gift. I wrote them a letter to put in writing what was going to be spent, and that was the end of that. I spent the money on what was essential.

At this time I had an ad sales person and a graphics person. And myself. The graphics person was using this old Compugraphic machine. It had been upgraded since the last time. The way the Compugraphic machines worked was that it was a photo process. You type this stuff in and the actual paper, which is photosensitive, goes into a drum--a container--and then you take the container into a developing process and it comes out as type. The problem is that the container sometimes leaked, and that meant that whatever had been typed was dead. It's the same problems. We always had problems with typesetting, and now was no exception. We had nothing but problems with that system.

Tom Hanchett was doing the ad sales. He was doing great. Then I was thinking I had to get some help in here, except we didn't have any money for help. We didn't have any money for anything. I started calling around, and because we were a nonprofit I called Sawyer Business College. Sawyer Business College had student interns that we could get for twenty cents on the dollar. It was like a work-study program. We paid 20 percent and they paid 80 percent. It was a federally funded program for students who were going through business schools or something. But the problem was you could only have the people for three months [laughs]. We went through a lot of these people while they were going to school at Sawyer Business College. See, you don't want them the first three months because they don't know anything. It's like a six- or nine-month program. Sometimes we were lucky and got nine-month program people, and so then they were working for us for six months instead of three. At one point I think I had three of these students working simultaneously because I figured three dollars an hour is pretty good.

We had a Scriptomatic machine, which is how we addressed the magazines. It's kind of like an addressograph machine. They're cards, and they have this kind of carbon stuff on the back. You put a stack through the machine and it addresses the back of the magazines. You have them sorted by zip code, it's mechanical; it's very hands-on. It's one card at a time, and you had to do it by whatever the division was that you needed for the zip sorts so that you could mail them bulk. We were mailing 12,000 copies a month this way. That translates into a hundred sacks of mail,

which is just around a ton of magazines. Me and my secretary were doing this work [chuckles].

The first time I did it--this is back a little bit--Andy showed me how to do this. Thank God I'm smart, because he really expected that I would never be able to do this. But I paid attention closely and basically I did a flawless job. So flawless in fact that six months into this program, which is another story, the post office calls me. Whenever the post office calls you when you do a big mailing, you're in trouble [laughter]. But it was a funny kind of call, and I should have had it taped because the guy calls up and he says, "Hello, this is the post office down at Midway." I said, "Yes?" He said, "Are you still mailing Mainstream?" I said, "Well, yes, we mailed it yesterday." He said, "The reason I ask you is because we never see you on the dock sorting mail anymore." [laughter] Oh, my God--you mean every month--and I had watched this process once and we got it down to where we had no problems. We had never been called by the post office. That's like a compliment [laughs].

Breslin: Absolutely. No more need to be standing on the docks with a bag zipping through the numbers.

Jones: But the two months I said I would volunteer turned into four months. The four months turned into two years. Now we are at the summer of '84. There was something in the middle of there that I wanted to--oh, we went on glossy stock. We had been on newsprint for a while and a little bit of book stock for a while.

The way we got on glossy stock--again, for the second time--was someone came and sold us. They said, "You can be on glossy stock--spot color--and we'll do the mailing." It was only going to cost me \$1,000 more a month. That's up from newsprint. I thought it would be a good deal because then we could sell color ads because it wouldn't be on book stock or newsprint. The problem was we had to convert all these Scriptomatic cards to a computer program so that that could happen. We spent weeks doing that job. October of '83, actually, was when we went back on glossy stock after many years of being on newsprint.

Now instead of being printed in San Diego it was being printed in Pontiac, Illinois. There are a lot of printers in the Midwest. They have cheap labor and access to paper and they've been there forever, so the cost of land and building isn't as high. That was the reason we had to be on computer, because we had to be able to send them our mailing list; we couldn't do it by hand anymore. People got the magazines faster. Basically it was a good deal. It increased our cost \$1000 a month, and that

translates into \$12,000 a year. We had to then offset that by selling more full-color ads.

Breslin: How were you supporting the direct costs for the magazine? Through ad sales at this time?

Jones: Yes. When I took over it was right about at \$100,000. But you had to pay for the graphics person and the ad person and you had to pay for the rent and the printing and the mailing and all the overhead: insurance, everything. There was no extra money.

Mainstream, a National Magazine

Breslin: Was the magazine functioning as a magazine rather than a training program at this point?

Jones: Oh, yes. We didn't have any trainees anymore because that was gone. Actually, during the interim when I wasn't there--between '77 and '82--they had taken it from a San Diego magazine to a California magazine to a national magazine. Now when I took over it was interesting because even though they were selling it as a national magazine, they were not doing national stories. They were still doing these stupid things like wine and cheese tasting fundraiser at so-and-so's in San Diego. The first thing I did when I took over, besides telling everybody "I'll eventually pay you," was I quit taking local phone calls. The first phone call --"We don't do that anymore." Over the course of the next six months or so we quit getting those calls, which was good because I didn't have time for them anyway.

So we eliminated all the local stuff and we started pushing out on the national stuff, which is what they should have been doing two years earlier. That first year we were the first people--it was in '83--to do a head-to-head comparison of all the wheelchair companies. We did a double spread on all the wheelchair companies that we knew about or could find. We did a photo of their product and we did all the characteristics that we could think of that anyone would need to know to make a buying decision. Our philosophy was always that the magazine would give people the power to choose. If you don't have the information and you go into your local dealer and you need a wheelchair, what are you going to do? They're going to sell you what they have on their floor, whether it fits you or not, whether it's the kind you need or not. Whatever is on the dealer floor is what you're going to get. So we always felt that if we could provide

consumers with information, they would have power. It didn't quite work out that way, but that was always the driving force.

Breslin: Let me just ask you about the management structure. The board was still in place at this time, and you were editor and publisher?

Jones: Yes. We were like a wholly owned subsidiary of Able Disabled Advocacy.

Breslin: You were basically in charge of everything.

Jones: Running the show.

Breslin: Were you in charge of all the editorial decisions at this time?

Jones: Yes.

Breslin: Did the board have any responsibility for that? Or interest?

Jones: No. They didn't want to do anything. They're glad if I was doing it all. They would be glad if they didn't even have to come to meetings [chuckles].

Breslin: What was your motivation for committing yourself to the magazine at that level during that two-year volunteer period?

Jones: Mainly I felt that we, the community--Jim Hammitt, et cetera--had worked too hard to get this magazine to be a voice for the community to give it over to some nondisabled person with a rehab mentality. If this other guy got the magazine, what would it become? It certainly wouldn't become what we had hoped it to be. It would just be another rehab magazine from a nondisabled point of view.

Breslin: What was your idea about what the magazine was to be about at this point? You've mentioned a little bit about the product options.

Jones: We felt that by giving people information they would have power to make decisions. Part of that was political stuff going on, part of that was sexuality stuff going on, part of it was housing, part of it was products like wheelchairs, vans, computers and that kind of stuff. We just felt that what was lacking was information, and if we could provide a forum for people to either write in and get answers or receive the magazine and get answers to their questions, or even being a part of a community. The disabled community is so spread out, and a lot of times you didn't have buses in those days with lifts, barely, and

you didn't have ways for people to get together. Few people had their own vans. What was happening was the community couldn't gather in one place at one time, and still can't, really. There are no hotels or convention centers that could hold a real meeting of the disability rights movement. It doesn't work. Our idea was that we could provide the information going into the homes, and that would be like a surrogate meeting place. A good idea.

Breslin: Do you have any practical or theoretical relationship with what was going on in northern California at that time in terms of the politics of the movement?

Jones: In '77 I know that the sit-ins were happening up here, and we did report on those. I'd have to go back and pull those issues at the time. We reported on the White House conference. I don't remember, I'd have to go back and look at what we really covered. We tried to cover whatever we heard about. Since there were only three of us, we really weren't doing a lot of outreach. We basically were responding to information that came to us, and that was the way it had to go down. We didn't have the money to do a lot of long-distance calling. We didn't have any staff, basically. So when we heard about things we could do them, but we weren't like investigative reporters.

Wheaties Competition, 1984

Jones: In 1984, the Wheaties thing. We're proud of that. One day I was going down the cereal aisle in the grocery store and there's this Wheaties box. It has this cut-out figure of a ghost. It says, "You can be on the Wheaties box." It was the thing about sending in your box tops and the group that gets the most box tops will get their person on the cover of the Wheaties box. I thought, "Oh, well, we can do that." [chuckles] So I called up Andy Fleming at the National Wheelchair Athletic Association and I said, "Do you know about this Wheaties competition?" He said, "What are you talking about?" I said, "Wheaties is having a competition right now. The six top nominations will each have their image on a million Wheaties boxes. I have no idea who the players are, but I'm sure you or your member organizations know who could garner the most votes nationally. It won't do for the tennis people to nominate their person, and the basketball people to nominate their person, and so on. You guys have to come to a decision about who you think has the best chance of winning. When you find out let me know and we'll publicize it."

I wait, and there's no answer. I wait, and there's no answer. Time is lapsing and there's no answer. Finally they send me something that says they want to put George Murray as the name. We start publicizing this, and we did it. George Murray got on the cover of the Wheaties box. Well, they announced it in February of '84. Wow, we did this. Millions of people sent in their box tops. The thing that was really marvelous was George Murray was a Boston marathoner. He was one of the first wheelchair marathoners that actually competed at a similar time to a nondisabled runner. Before that, Bob Hall was actually the first wheelchair marathoner, but his times were slower because his wheelchairs were--even though he's a wheelchair designer and developer, it was before he really started redesigning the chairs. So George Murray was one of the top winners. This was the year of the Los Angeles Olympics; it was 1984. Because the other five people who had won the right to be on the Wheaties box were competing in the Olympics, they couldn't have their image on the Wheaties box until after the Olympics because they would be disqualified from competing in the Olympics. And I'm not into all the politics of it.

Breslin: Some commercial endorsement.

Jones: Commercial endorsement or something. So because George wasn't competing in the Olympics, he was the only one that they could put on Wheaties boxes until after the Olympics. As a result, instead of getting his face on a million boxes, he got his face on three million boxes so that Wheaties would actually have enough box covers to last through the L.A. Olympics. That was actually a wonderful opportunity. To me it says, as people picked up their Wheaties box they would see that people with disabilities do things. They're athletic. It was a real change in the attitude. I thought that was one of our coups in the early days.

Breslin: Let me ask you again about this connection within the national movement, if not Berkeley in particular. Other people with disabilities are doing things in the movement around the country. It sounds like you guys were really doing so well what you thought was the right thing to do, primarily, with not a lot of connections. Ultimately you did build all sorts of relationships with people all over the country, but at this point that was not what was going on.

Jones: At this point we were trying to survive. It was really tough. So we were doing what we could do. But I wasn't really connected. I was trying to think of when I really started. In '86, maybe. At one point during the time that I was volunteering, Evan Kemp called. I think Bob Funk was at DREDF

[Disability Rights Education and Defense Fund] at that point in the early eighties. I can't remember exactly when it was, but somewhere around '84, the California Republican Convention met in San Diego that year. Evan was flying into the airport from Washington, and he couldn't get from the airport to the hotel. We all know how that goes--no transportation, even for a presidential appointee.

Breslin: It was the national convention.

Jones: No, it wasn't the national convention. It was the California state caucus of the Republican party. They were meeting in San Diego, and June Kailes and Gordon Anthony were there and some other people. The interesting part about it was that Evan couldn't get from the airport to the hotel so they were calling around. This was a Saturday morning he was flying in. They called me to see if I knew anything about transportation. Now not much has changed, because we had that same discussion three days ago here of how to get from the hotel to anywhere. Nothing's changed in some regards over the last fifteen years. I said, "We'll pick up Evan at the airport and take him to the hotel." That's exactly what we did. We picked him up at the airport, and Bob Funk and Janine and took them to the hotel that the meeting was happening at. The thing that was going on that day was we were supposed to be at a wedding. Because things didn't jell quite right we were late. We actually came in after the bride at the wedding. But that's the way it is. What are you going to do? Evan would be stranded at the airport, right? That was the first connection, really, with the outside.

Breslin: How were you figuring out the issues to write about? They were coming to you, I guess. Say a little about that.

Jones: I don't know; it's really foggy. Maybe it's foggy because we were so stressed out with just trying to survive. We were doing stories. We did a story about Ralph Beirneschke, who was a San Diego Charger, that's a local story. He almost died, and he had colitis. We did a story about George Murray. We did stories about discrimination, stories about employment in those days. We also did stories about the labor statistics and we did stories about interviewing. Every issue had something about employment. There was an employment column in every issue for years and years. We actually did get some EEO [Equal Employment Opportunity] ads from some of the major corporations that helped the magazine along. At one point, EEO ads made up 33 percent of our ad base. It was a huge amount. It wasn't a lot if you look outside, but percentage-wise it was a big chunk of our ad revenue--which basically died out about three years ago when affirmative action went in the toilet.

We did this one on lightweights, and we had a picture of Nancy Sawhney lifting this little Quickie wheelchair above her head. We picked the place to have it where it was kind of like the edge of a cliff, and so here's what looks like a young woman --she's muscular, but you wouldn't know that by looking at her. We put her in this old clunky wheelchair, and we had her lifting this Quickie above her head. The headline was, "Lightweights coming on strong." That was one of our favorite covers because it was a real good image.

We did stories about ramps to nowhere. There's a curb cut, and then right in front of the curb cut? Steps. What are you going to do after you get across the street? We did stories on libraries. We had this library that says, "Wheelchair access, ask inside." There were three or four steps. We took one of our friends down there, and we had him holding a megaphone and yell "Access!" It was kind of fun. But these were real issues. We did stuff on transportation and attendant care. Real issues that people would think about.

Bill and I mostly would think about what we needed to do, and we'd sit down and try to do it. It's hard to remember unless I actually look through the issues, because it's kind of a little fuzzy between where that ended and where we took over and what the differences are.

Purchasing Mainstream, 1984

Breslin: Why don't you start to talk a little bit about that? When did you take over?

Jones: We took over in '84. By the way--this is historical--the L.A. Olympics didn't host the Paralympics. It was embarrassing to the U.S. wheelchair athletes because every other time for many, many years the Olympics and the Paralympics are held in the same city. But the L.A. Olympics with Peter Ueberroth, who was so proud of how he did the Olympics, couldn't fund the Paralympics. They wouldn't do it. The Paralympics couldn't raise the money, and the U.S. Olympic people were such assholes. They started making restrictions on how the Paralympics could raise money. Because Paralympics sounds like Olympics, and they didn't want the sponsors to be confused, they started making real constraints over the fundraising. As a result the Paralympics was held in New York and in the United Kingdom that year. It was a huge embarrassment to the wheelchair athletes here.

Four years later they were held in Seoul, which did a great job. They were held in Barcelona, and they did a great job, and then later remember to remind me to talk about the Atlanta Paralympics.

So here we are in '84 and the Olympics had just happened. This was the first year that they had a wheelchair exhibition in the Olympics. Sharon Hedrick won the 800 meter, I think. I'd have to go back and check the statistics on this. I can't remember who won the men's 1500 meter. But it was the first time, and the race was actually on national television. It was some stupid hour like eight in the morning on Saturday morning, but it was on national TV. It was the first time that they had had this exhibition race in the Olympics. Maybe that was because they were guilty that they had screwed them up so badly, I don't know. That was in August.

I had been volunteering at the magazine for two years. In June I told the board, "You guys haven't raised any money, and you don't seem to have a plan. There's no more plan than there was two years ago, unless your plan is just to let me keep working."

Breslin: For free.

Jones: They said, "Okay, we'll talk about that next month." I said, "Okay, put it on the agenda for July. That's fine." Then they met in July and they didn't talk about it. Then they met in August and they didn't talk about it. Then they said, "We'll call a special meeting," and so they met the fifteenth or so of August to talk about it. They came back and offered to pay me \$1000 a month to run the magazine. It's not a lot of money, it's less than I would want, it's okay, except there was no method for raising that \$1000 a month. If I thought they really had a way to think that they were going to raise the money, that would be one thing to even say that that's less than I want but it's acceptable. But to think that I was going to have to then raise that money myself, I don't think so. I told them that I was going to take a two-week vacation. I had it coming, I was volunteering anyway, so I said I was going to take two weeks' vacation.

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Jones: I got the magazine done before I went on vacation. I finished it up, I shipped it to the printer. I thought, "Oh, God. This is it. This is the last issue of the magazine."

We went on vacation, and Bill and I actually took a train ride up to Oregon. We stayed in a friend's condo. It was an accessible condo on the beach in Oregon. But it really didn't feel very satisfying; it wasn't a very good vacation. After the first four months of volunteering they started putting on the books \$500 a month for me. Not that they were paying me, but it was accumulating at \$500 a month. Okay, so it's on the books. So then they said to me, "If we sell the magazine to so and so, what would you do about the money that we owe you?" I said, "Well, you're going to pay me." They were basically finagling how they weren't going to pay me the money, but they were going to give the magazine to someone else.

I said, "I think if you do that you probably need to pay me. It's a debt from the organization," even though in reality I had never had any anticipation of collecting that money. Then they said, "Would you buy the magazine?" I said we'd think about that. What happened was we assumed the debt that they had, which mostly was to me, and there was a little bit of money to a printer that they owed. Little bits of money. I think it wound up being something like \$17,000. Now that was in '84. It was a chunk of change.

We assumed the magazine on November 1, 1984. They stalled on everything. It went on for weeks and weeks after the decision was made. This issue that was at the printer--that I had gotten to the printer before I left on vacation in August--which was an Olympic cover with Sharon Hedrick--and you have to understand that during the Olympics there was a photo pool. That meant you couldn't send your own photographer; you had to use the photos from the photographers that went into a pool. The thing was that this was the only vertical photo of the wheelchair races. The others were horizontal, and to do a cover you need a vertical. Well, in between times, of course, Sports and Spokes bought that photo as well. They were available to whoever would buy them. So out comes Sports and Spokes, and our copy is still at the printer because we were trying to transact this transaction. So our magazine comes out after theirs, with the same cover. We would have beat them by two months even though we weren't a sports magazine. Then I get this note from Nancy Crase saying, "Imitation is the best form of flattery." Oh, man.

Breslin: Who is she?

Jones: She's the editor of Sports and Spokes. I was so pissed. We would have beat them by two months. But that's okay.

Breslin: Tell me about the nature of the takeover of the magazine. Was it simply a transference of the debt from the previous corporation to you?

Jones: Right. And we got the trademark for Mainstream. That's about it.

Breslin: You had to reassume the debt and to take over--

Jones: And the liabilities.

Breslin: And any assets if there--

Jones: No, we didn't take any of the assets except the name and the files. In other words, we had to do the subscription files because we had to serve the subscriptions and the advertising files. But we didn't take the file cabinets; we took no hardware. There was no hardware transaction. It was just the files and the name. That's all we got. And the debt. It was okay. By the way, the new corporation name was Exploding Myths, which nobody ever knows because it's not something we publicize. We always publicize Mainstream. But the corporation was Exploding Myths, which owned Mainstream. Mainstream was a DBA--doing business as. So what was the question?

Breslin: I was trying to understand the business arrangement when you purchased the paper. You had to repurchase all the hardware? The office equipment and so on?

Jones: Everything. We never had much. In those days if you had a 256K computer that was a big computer. And we bought an Epson LQ-1500 which I still use in my office. It is still cranking out. You know, if it's not broke, don't fix it. We bought that computer, we bought a typewriter, we bought used furniture at a used furniture place. We bought three desks and a couple chairs. It seems to me we spent less than \$500. The best advice the lawyer gave us was to move out of the building. Thank God we moved, because there was a little bad blood in the thing. Where we wound up moving was three blocks from our house. The rent was cheap: we were paying \$275 a month. I could wheel over. Actually in those days I wasn't using a scooter; I was using my crutches. So I'd drive over or whatever. I mean, it wasn't too far. It was easy.

Breslin: Did Bill have a hand in helping you make the decision?

Jones: To buy the magazine? Oh, absolutely. We're married. We're partners. I couldn't have bought it if he didn't want to. We just didn't want to see it die. We invested too much in it

emotionally to just let it go. We took over in '84. My parents mortgaged their house for us, and we used that money to sustain us while we really tried to get lift-off of the magazine. We didn't transfer receivables--besides that, there weren't any receivables because the last magazine that they published was in July. So now we're talking November, so basically there were no current receivables except bad debt. So all we had at that point really were liabilities. We borrowed money, and we started doing what we do. We were making sales. I had a secretary and a salesperson. We contracted out the graphics at that point. We weren't doing the mailing anymore; that was still done at our printer in Illinois. So there were basically three of us doing the magazine.

Breslin: Did you bring the people who had been working with you previously to the new operation?

Jones: Yes. It was Martha Higa, who was my secretary, and Jennifer Chipman, who was my ad salesperson at that time.

First Use of Scooter, 1984

Jones: One thing that happened at this time and a little bit before was that--I'm always concerned about my weight. I've been on Weight Watchers and all these different programs forever. I went on a program at a real hospital, Scripps Clinic, in San Diego called Forever Thin. I thought, "That's a good title if it'll actually work." So I went there and their program was that you go on this nutritional diet--it was regular food, not diet food; it was just watching your calories. Then they had this walking program where the first week you would walk five minutes a day, and then you'd walk ten minutes a day, and then you'd walk fifteen minutes a day. By the third week I was dead. The problem was that I had asked them--because I knew about post-polio syndrome--"Am I supposed to be walking?" I asked the exercise physiologist. He said, "Oh, it can't hurt you." Wrong!

Breslin: Didn't have a clue.

Jones: It was absolutely wrong. By the end of the third week I couldn't get up the steps of my house. It's three steps, and we have a ramp on one side and three steps up the front. I had always gone up the steps because it was shorter and it was easier. I got to my house, and I could not get up the steps. Finally I did get my leg to work and I thought, "Oh, my God. Deep trouble." I sat down on the couch and I was really pissed. Those people didn't

tell me the truth. He didn't know the answer; he should have looked it up, but he didn't. He didn't care. As a result of that I really couldn't walk very far after that. In the past if I had walked a few blocks it was no big deal, but now I really wasn't able to do that.

Breslin: You never got the function back. It knocked off the nerves?

Jones: Yes. I got some function back, but it was never like what it was before. So that happened in that transition period too. Shortly after that I got a scooter. I needed it. I quit going places. We quit going shopping. I couldn't do it anymore. Not that I can't walk around, but I can't walk around very far [chuckles]. That happened in the summer of '84 as well.

Focus on National Disability Issues

Jones The next year, in '85, there was a Live conference in Los Angeles. I think it was Martha Griswald. She had this conference. It was really post-polio, but it was independent living. I went up there, and I was actually sharing a room with a woman also who had post-polio syndrome. Then a funny thing that happened that weekend was ADAPT [American Disabled for Accessible Public Transit] was doing a demonstration in L.A. I knew they were, and I hired a photographer to come up and do the photos of that. We were actually doing better news coverage after we took over. David Stone was our photographer, and he also had a mild form of cerebral palsy. He went up and did the photos of the people getting arrested--Bob Kafka and Stephanie and the crew. They always have this long parade the first day, and that was the first day I really met Mary Johnson from The Rag. We actually roomed together at the ADAPT demonstration.

That's when I really realized I needed a scooter. They were at the park, and they were going to go out for this parade they always do, and I got one block and couldn't go any further. That was it. Done. I couldn't do it. It was really interesting because in a group of people with disabilities I felt really disabled. I couldn't keep up. They said that they could loan me a manual wheelchair, but I can't push a manual wheelchair. That's no good for me at all. That's when I realized I had to start dealing with getting a scooter. That was November of '85. That ADAPT demonstration was the cover of the November issue.

That was also when the Air Carrier Access Act was happening. Just before that--that happened the next year, actually--but that was when the case around it started developing.

ADAPT was doing this stuff on Greyhound buses. Nothing's changed: we're still doing Greyhound buses. I wrote this editorial about how the people who ride buses need to support the people who use airlines. The people who use airlines need to support the people who use buses, because this is really an economic issue between rich crips and poor crips. If we don't help each other there won't be enough of us to do anything. I really felt the need for people to--I said, "If you ride an airline, first write your letter to the bus company. If you ride the bus, write your first letter to the airline." Do the other people's task first, because if you do your own thing first you'll never do the other people's. I really wanted people to understand that there's a lot of solidarity that has to happen. We have to see each other's issues as our own issues. It was a wonderful issue. It had a cover of Ken Zola, who was the president of the California Association for the Physically Handicapped at the time. He had his fist raised. Talk about an advocacy pose. Here he is in a wheelchair with his fist raised, and the signs and the background and the media. We got a picture of the television camera. It was a really good cover. That was a wonderful issue.

We did stuff on Elizabeth Bouvier. That was before we took over. I'm trying to remember some of the issues we did. Right to die.

Breslin: Let me just ask you about how you were finding out about some of these issues, because these are issues of national significance to the movement.

Jones: Some of it was because Bill was at the newspaper. Sometimes he would see stuff, and we would pick up on it. Sometimes people would call us, and sometimes people would invite us to things. How do you know what's going on? You try to be open to all forms of communication. You might see something in the newspaper, Bill might hear something that comes through the newspaper and because it has to do with disability they were funneling some of the stuff to him.

Sexism at Leadership Conference, 1986

Breslin: How do you think you were being perceived by the movement nationally at this stage?

Jones: I don't think we were.

Breslin: Really?

Jones: I don't know. Maybe people were starting to think about us, but I didn't get the sense. I don't know. It's hard. Sometimes you can't see yourself from the outside. I didn't have the sense that people were writing to us a lot. They weren't calling us a lot. They weren't communicating with us a lot. That would tell me that they didn't perceive that we were open to doing their stuff. A lot of stuff was going in The Rag at the time. It was really a lefty publication. I don't remember much of that. I don't think that people were really calling or writing us. They certainly weren't sending in their subscriptions. How's that?

The next year was '86, and I was invited to a leadership conference in Washington. Were you there? I remember Bob Funk was there. I don't know when you took over DREDF. At any rate, Bob Funk, Justin Dart, all the boys, Mark Johnson, Max Starkloff, who else? Evan Kemp.

I go in to register at this conference. It's a disability rights leadership conference. I was really tired because I had night-flighted into Washington to save money. I get there and I start to register, and the thing's not going to start until the next morning. Phil Caulkins. I don't know if Tim Cook was there or not. I go to register and I'm standing there on my crutches--for some reason I was still on crutches; it must have been the next year that I got the scooter--and one of the boys says to someone else, "Let's continue this conversation in the bar." Then they said, "Mark, do you want to come along? Max, do you want to come along? Justin, do you want to come along?" They left me standing there. I was so pissed. I'm still pissed.

Breslin: Did they know you?

Jones: Yes, they knew me. But I wasn't one of "them." Number one, I wasn't seated. And number two, I wasn't male. Except you have to understand I come at this having just spent several years doing women's ordination of the priesthood organizing [chuckles], and I thought, "I'll be damned if I'm going to work in a fucking movement where they want us to lick stamps and they make the decisions." I was pissed. First of all I was shocked that they

weren't even courteous enough to invite me. I was just livid. Even now talking about it. I was flabbergasted.

So I went upstairs to my room and I just started to cry. I cried and I cried and I cried. I thought, "We can't have this this way. I am not going to work in a movement where we're not treated as equals. I'm not going to do it."

The next morning Bob Funk called me and wanted to come up to the room. I said, "Sure, come on up." I was really pissed. He said, "Well, we really didn't mean it that way." I said, "How would you expect me to take that?" He was trying to schmooze me over and I said, "That's okay. I know where we are. I got the message."

I go downstairs for the first meeting and Phil Caulkins comes over and talks to me. He was trying to schmooze it over too and I said, "Any time I see sexism at this conference I'm going to nail you fucking bastards." I was just out there. I was so pissed. I'm not going to have this stuff. I don't know if you want that on the tape.

Breslin: I personally want it on the tape [laughter]. Tell me what you think the basis for it was. Tell me what the origin of that is.

Jones: Why the sexism?

Breslin: Why did they do that? What was their motivation for excluding you?

Jones: I don't know. I felt it was a sexism thing.

Breslin: That's it? Straight sexism?

Jones: I don't know. That's what I thought. That's how I perceived it. That's what it looked like. If it walks like a duck, quacks like a duck--. Maybe they didn't want me involved in the conversation for other reasons, but the other thing they did at the conference was they isolated me. They put me in some subcommittee group that didn't have any other members! Then I was wondering, "Is it they think I'm powerful that they want to isolate me?" Then because they realized that the group I was in didn't have any members, they sent in Gordon Mansfield to be in that group.

Fast forward. We go through all this meeting. Sunday morning--we were still doing this meeting--we had organized to have the women's luncheon. We just decided the women that came to this conference were going to have lunch on Sunday.

Breslin: Who were they?

Jones: Mary Johnson was there, who by the way is not disabled but runs The Ragged Edge. It was The Disability Rag but is now The Ragged Edge. Marca Bristo, Mary Jane Owen, I think Kathy Martinez but I wouldn't swear to it. I don't remember. I really didn't know all the players. But there were maybe twenty women in that room. Maybe Pat Wright. I don't remember who else was there.

Breslin: Was this the first national leadership you attended?

Jones: Yes. You're going, "Who the hell am I?" [laughs]

Breslin: No, no, not at all.

Jones: The answer was yes. Well, I had been to the White House conference--as a media person, not as a participant. It was '77.

I knew Mark Johnson because we had been at the ADAPT demonstrations together. Several of them by that time. I had been at the one in L.A. where I first got initiated into ADAPT. I had gone to one in '87, where it was the transportation--actually, that ADAPT demonstration in San Francisco in '87 was the one that broke through the ADAPT/APTA [American Public Transit Association] action because it was the spouses of the people at APTA that were in tears. They said, "How can you be denying these people the right to ride on your bus?"

Breslin: That demonstration was in '86.

Jones: That was '86, that's right. So I knew Mark Johnson. I had known Evan and Bob because I had given them a ride in San Diego.

Breslin: How did they know you were angry when the initial--

Jones: Oh, because Janine was standing there. She calls herself the AB [able-bodied] gopher. She was doing the registration. She's sitting there behind this table registering me, and all these guys wheel off to the bar and she looks at me, and I look at her and I said, "Did that just happen?" She said, "Yeah, that just happened." I said, "I am just so pissed." I was also on jet lag. I was tired. So my emotions were really to the surface, and they're still to the surface because it was a powerful thing for me. I just started to cry, I was so pissed. I thought, "We've got to get beyond this." I still don't think we're beyond it now. This is my opinion. There's still a lot of work to do.

At any rate, on Sunday afternoon lunch we were going to have all the women upstairs. We had a room for all of us to have

lunch. The guys were very nervous. They were very nervous. In fact, what happened was they sent people to see if we were done yet. "No, we're not done yet. Go away." They kept sending spies to the outside of the room. What we decided in that meeting was that a lot of the women had been feeling the same stuff in different ways. Mary Johnson and I had decided that we were two of the disability press, that we were both women, and we had control over the media. We had realized that we had been quoting men in our magazines, and we had been doing cover stories on men in our magazines. We decided that for the next six months we would not do that activity. We would promote women in our magazines. We did a cover on Marca Bristo, we did a cover on-- oh, I can't remember who all. If we ran a story where we were going to do quotes, the woman was going to be quoted first. We were going to elevate the woman profile in the disability rights movement. That was what Mary Johnson and I decided we could do at that point to elevate women's roles in the movement.

We also decided that we could elect Marca Bristo to be the president of NCIL [National Council on Independent Living]. She became the president of NCIL. We did that. We lobbied and basically we called in all the chits. As a result of Marca becoming the president of NCIL, she became the president of the board of NCD [National Council on Disability]. I'm proud of that strategy.

Breslin: Did you report back to the guys what you all decided to do?

Jones: No. We didn't need to tell them that we weren't going to quote them anymore. Just don't quote them anymore. We didn't need to tell them that we were going to elect Marca; we just did it [laughs]. What do they need to know? We didn't want to give them a strategy to fight against. So that was that little episode.

Breslin: What time of year was that meeting?

Jones: It was like May. Around the president's committee [President's Committee on Employment of the Handicapped].

Breslin: In 1985?

Jones: In '86. President's committee in '86. They backed it up to the president's committee because people were flying in for the president's committee and they could then stay over for this meeting which was actually a three-day meeting. I gave them a really good idea at the thing, but no one acted on it. It kind of died.

Breslin: Did this meeting change your relationship to the national leadership?

Jones: I think it put them on notice that I wasn't taking any bullshit from them.

Breslin: Not just the boys, but--

Jones: I think it elevated who I--I had already known Mary Jane Owen because she had written for us. People who were writers or in connection with us had been in contact. Mary Jane had written for us. I can't remember some of the other people at that meeting. I think it introduced me to some of the people. I have a big mouth, pretty much.

Breslin: I think that you hadn't really been in situations where the national leadership was formulating strategies or whatever up to this point. You had been relying on some secondary ways of getting your information.

Jones: That's right.

Breslin: So this was a moment where you really, even though you knew some people individually, were an active participant for the first time.

Jones: That's exactly right.

Breslin: Did that change things for you in terms of the direction of the magazine or the issues that you were doing? Obviously you did in terms of the women's focus. Were there any other?

Jones: I was really pissed at Phil Caulkins. The reason I was mad at Phil is because I think he was the one that instigated the first thing, and I think that's what happened. I think he said to Max, "Let's go off and finish this conversation." So he was really the instigator of that exodus. Tim Cook called me. I love Tim Cook. [begins to cry] I'm really sorry about him.

Breslin: Yes, he was neat.

Jones: So he called me up a couple weeks later and said, "Why don't you call Phil and make up with him?" I said, "Why doesn't Phil call me and make up with me?" He said, "Blessed are the peacemakers," because he comes from this Catholic background. I said, "Tim, make no peace with oppression." So we were bantering back this stuff--

Breslin: The Catholics and the Episcopalians [laughter]--

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Jones: He was trying to bridge this chasm that had happened at this meeting. This was like the next week or so later. He said, "Phil will never call you." I said, "Then that's his problem. The phone lines go both ways." I wasn't going to apologize to Phil. I wasn't going to do that. We just kind of left that out there.

In the meantime Tim was writing for us. Tim was writing on all this stuff from PILCOP [Public Interest Law Center of Philadelphia] that he was doing and all the court decisions, and I could go back and pull all that stuff. It was wonderful. I should composite it because it was a wonderful set of pieces.

Breslin: As an aside, you guys should publish that separately sometime. I do mean as part of your current project.

Jones: Tim was such an imp. He was so smart and so funny. God, where would we be if he was still here? Sad.

Forward a little bit to '88 and there was the [George] Bush-[Michael] Dukakis race. We were trying to get out the vote. We put both of their pictures on the cover of the magazine. Tim suggested that he could write a piece on Dukakis, and Evan would write the piece on Bush, and we would have it head to head on the cover of the magazine, which is what we did. Tim was working for the National Democratic Committee at the time. The day we got the magazine on the boards and shipped them out to the printer--it was a Friday night, Saturday morning--one of those times where we were working really late to finish on time, in the mail came a package from the National Democratic Committee, and it had a press release with my story. My story had gone out as a press release to everybody as if I had picked up that story and ran a free press release.

Breslin: How did that happen?

Jones: Someone in a position of power mailed it out.

Breslin: Do you want to say who?

Jones: I don't know. But somewhere between Fred Fay and Tim Cook probably had the deal going. Somehow or another I wound up talking to Fred Fay about this. Fred said, "When Dukakis wins I'll get you an interview." I said, "What if he doesn't win?" I was pissed. I said, "I want a retraction. I want you to send out that you're not going to have anybody able to run that." I was embarrassed, as if I would pick up--. That's not the way we

did cover stories. It made us look really cheap. We had been working on that story for a long time.

Breslin: You commissioned a story from him.

Jones: That's right. Then Tim says, "Well, I won't take the money." I said, "That's not the issue." He says, "What do you do when this happens?" I said, "I never let the people write for me again." He said, "Well..." I said, "Well..." And that ended that relationship. It never really got reconciled before he died, and that was a real sadness to me. But that's okay--it happens, it happens.

I was angry. I thought, "These people don't understand anything."

Tenth Anniversary Issue Moves Magazine to Higher Level, 1985

Breslin: I was going to shift gears a little bit and have you think about what level of disability awareness you were at, say, in '82 to '84 compared to '86 to '88. You're really dealing with the highest level of disability issues. You're dealing with presidential campaign politics. The highest level in terms of political decision making--maybe not the most complex issues, but certainly the ones that are most visible--compared to a curb ramp in San Diego. You were doing a lot of other stuff, but it seems like the level of sophistication was really growing and changing over those years. Is that accurate?

Jones: Yes. When I took over in '82, the magazine was still a local magazine although it was taking national subscriptions and national ads. But it was a local magazine. When I took over, like I said, I quit taking any local calls. And in some conditions I quit taking state calls. I was really focusing on having it be what it said it was: a national magazine. As you said, you can tell the difference. I started doing things differently. I started calling people. I started looking at things differently. I wasn't looking at local issues anymore; that was not going to get in the magazine. Occasionally local things did if it was nationally significant, and occasionally that happened. Mainly I was looking at national issues.

We also had some wonderful pieces from people like Ed Hudak. We did this thing on post-polio, on the iron lungs. We had a great graphic of the iron lung sitting in the field growing old. There were some wonderful pieces that we did, that we

commissioned. We ran a piece by Irv [Dr. Irving] Zola. That may have kicked it off, actually. Our tenth anniversary issue was actually in 1985. We had a piece on the independent living movement by Ed Roberts. We did a piece on religion by Mary Jane Owen. Bob Funk wrote a piece on politics, I think. I can't remember who did the education. There were like five pieces that were kind of like where we are right now. That happened in '85, and maybe in some ways that kind of pushed us into a different level, because it was like a snapshot of the independent living movement in 1985, which was like ten or fifteen years after it had really gotten off the ground. It was a wonderful set of pieces.

We did our twentieth anniversary issue too, and that one looked back at all the issues that we had done and the stories we had done, and where we had come from and where we began. Not just us at Mainstream, but a short--when I say short, it was only like an eighteen-page paper; that would be about what it would wind up being--of the movement.

Breslin: When was that?

Jones: That would be '95. So I think maybe that, and also going to the ADAPT demonstration in '85 in L.A., getting familiar with some of the players, running that tenth anniversary piece--it was a whole shift in attitude. We took over the magazine in November of '84, so really when you look at it we did a lot that first year. We redesigned the magazine, we upgraded the color, we did better product focuses--a lot more in-depth. It was a full-court press that first year. I also was an entrepreneur. I thought, "Someone's going to catch up with us. We'd better run like hell before someone catches us. We're in the lead right now; we need to push hard." But we pushed hard until we basically couldn't push anymore.

Also when we picked up Evan at the airport and did that Republican thing in San Diego, after that meeting, Phil Caulkins was working for the National Democratic Committee. He was working for the national Democrats. In those days they had the women's desk, the black desk, the disability desk, and Phil Caulkins was working at the disability desk. I wrote to whoever the head was of the National Democratic Committee.

Breslin: The one that died.

Jones: Yes. I wrote him and said, "Look here, buddy. You guys are giving away the disability vote." Who am I to tell him? But I did. I said, "The Republicans came here to wine and dine the leadership in the disability movement, and they're trying to

figure out how to get the disability vote." I was telling tales. I had been invited to this meeting because I had given Evan a ride. So I turned that information around and I sent it to the National Democratic Committee. I said, "You guys better get off your duff. You take us for granted." I didn't get a response. Later Phil called me. It was probably hard for him to call me. He called me and said, "Consider yourself responded to. The letter I would have to write I could never get signed by anybody." Okay, that was the end of that. Bush won [laughs]. Hello? Bush won.

Mainstream Audience

Breslin: Let me ask you about your notion about the magazine. Who were you writing for during this late-eighties period?

Jones: We're never really writing for the very elite leadership. The magazine was always meant to be for the people that were behind the leadership, because in order to have a followership you can't be so far in front of the crowd that they can't see your dust. So we were always writing for that. What we perceive and still is a huge market that is in significant ways behind the leadership. I think we feel that now with the ADA stuff. We were always hoping that we could translate where the people were that were way out in front, and translate that into a position that would bring people along that weren't connected with the movement in any way.

The magazine was never crazy, crazy radical out-front leadership, because we knew that we would lose the people behind the movement if we were too far in front of them. So we would always put stuff in the magazine to put them in touch with people--not necessarily names and addresses--but groups that were doing things. We'd give them information that would bring them along. Kind of lead them. Like The Rag. Obviously, I like The Rag. But if you gave The Rag to most of the people who are disabled in America they would think you're crazy. You can't do that. It's like teaching: you have to take them where they are and you try to lead them to the next step, and the next step, and you try to get them involved. So that's who we were writing for. We were writing for people that were out there, maybe parents who had disabled children and they were frustrated with the whole school system stuff.

We got wonderful letters from people. God, this one said, "You saved my life. I was at the end of my rope. I had been to

every meeting for my daughter, and I was stark raving angry." I had written an editorial about how I was angry. She said, "You know, you gave me permission to be angry." She said, "The next day I called up the administrator," and basically she got it done, because it gave her a breather to take a breath and be angry about it and then take the next step. We got lots of letters like that that were just really powerful. People were not connected in any way, like this woman whose daughter was disabled.

We got a letter from a woman who had a young daughter, age two to four, somewhere in that age range. She had spina bifida. Maybe she was about six. The mother wrote to us because she said, "I think my daughter should be able to use a wheelchair, but my mother--the grandmother--feels I'm copping out by allowing that." The mother was in a really good place, but it was like a real societal issue of if you allow the child to use a wheelchair she'll never walk. "It's so hard for her to walk. Why don't I just let her use a wheelchair?" It's what you consider the disability rights model, but she was getting so much flak from her own mother, the grandmother of the daughter. You could feel that she was glad that she had a connection with us because it gave her strength to do what she perceived to be the right thing and even tell her mother, "This is the way it is."

We got letters like that all the time from people who were just trying to make their way. They weren't connected with the movement. They didn't know.

Breslin: Did you imagine that your audience included people with a broad range of disabilities?

Jones: Well, we all know about the disability rights movement. What do we know? There's a pecking order. There's a lot of dynamics. Originally the magazine was for what we would consider the core disabilities: mobility impairments and CP and polio. Of course polio, Bill and I both had polio. Muscular dystrophy and those things. Blind and deaf. Those were the core disabilities.

We also, as time progressed, were doing more in terms of developmental disabilities and psychiatric disabilities. We did a whole issue last year on psychiatric disabilities. It was real important. But you have to understand that just like you bring people along who are disabled but are not really in the movement, you have to bring the movement along too sometimes. People who think "that's not like us."

There's always been this thing in disability culture that has to do with "I'm not mentally disabled. I'm just physically

disabled." I mean, there's this whole thing, and where you get that from is when you're a child or a young adult and people treat you like you're mentally disabled. They treat you like you can't think. So in your mind you get real rigid on this fact that "I'm not mentally disabled." What we felt was that we needed to work on this a little bit in the movement, but that we couldn't do so much on it that it would alienate our readership. So a lot of times what you do is--like I said--you have to lead people a little bit by a little bit. You start doing a little bit now and then a little more, and that's kind of how we were moving things forward. Also through the news briefs--we did a lot of stuff on news briefs that were bite-size pieces on some of the disabilities that we were now including in.

Justin Dart and the Push for the ADA, 1987-1988

Jones: So in '88 was Bush-Dukakis, and Bush won. We started doing ADA coverage. We started telling people to write their congressmen, and we started telling people to do stuff. Let me back up a bit. Justin Dart came to San Diego on a meeting one day, and he invited Bill and I over to have lunch. What you have to know about Justin is he never eats. It's a real weird thing. I want this in this history because people don't understand. You go to lunch with Justin, and you eat and he doesn't. It's a little bit disconcerting the first time that happens. But that was the truth. We hadn't eaten, and it was past lunchtime.

He had this idea about the civil rights bill. He wanted to know our opinion. Did we think it could get done? I said, "Well, it's a Republican presidency. I don't know, Justin."

Breslin: Was this during his tour under the Major Owen committee? Was he going around to various communities as a function of his heading up that task force?

Jones: This was before that. So it might have '87, '88. I can't remember, I'm sorry. It all kind of mushes together in that period. You have to understand people were very frustrated because public transportation still was not accessible under 504. A lot of cities didn't have lifts on buses. A lot of stuff under 504 was not being enforced. Some stuff was being litigated, but basically there was a huge frustration in the community that here we had gone through all of this stuff to pass 504, and nothing was happening. That was the sense in the community.

Justin came to town, and he was there for a vocational rehab--he was head of RSA [Rehabilitation Services Administration]. So when was he the head of RSA? I don't know when it was.

Breslin: Up to '87.

Jones: He asked if we would support it and we said, "Yes, if you think you can get it passed, we'll help you." But I thought, "Oh, my God--trying to get a civil rights piece of legislation passed in a Republican administration." I said, "The only concern we have is that we don't want to screw up what little rights we have under 504. We don't want to kill it, even though it's not where it needs to be." So Justin went off, and they're still cranking this out in NCD meetings, I guess.

In those debates between Bush and Dukakis, Bush said he would basically sign the Americans with Disabilities Act [ADA]. He would bring disabled Americans into the mainstream. We couldn't get Dukakis to make that statement to save his life. We couldn't get him to say it, Tim Cook couldn't get him to say it. He wouldn't say it. He lost.

Now they're submitting the ADA to Congress, they're putting that in, and the magazine is pushing hard. Almost every magazine we have something in there about writing your congressman.

This was between the first round--from '86 to '88. Dukakis and Bush were running in '88, and we ran a photo on the cover of the magazine of Bush and Dukakis, and we do this debate between the two. In that same issue we ran a listing because we wanted people to vote. It was September of '88. We ran a listing of everybody who had signed on to the ADA. We wanted people to know who their congressmen were, if they were supporting it or not. We ran a whole page or two pages--it was tiny print because it was a lot of names--and we told people if their congressman had signed on to the ADA we wanted them to call and thank them. If someone was running for office they needed to talk about the ADA. We tried to raise the consciousness of not only our readers but the people in Congress. If they hadn't signed on, they should know it was going to cost them. For some reason we didn't really follow up on that to see what the result was.

The next year when ADA was introduced--I know they made some changes to step back a little bit on it--it got passed. Maybe some of that advocacy when people were running for office helped. I felt really good about that. Every issue for like two years or longer we ran something about ADA stuff. It almost got to the

point where we were embarrassed [chuckles]. It's like, "Don't you have any other stories?" [laughs]

Breslin: It was the dominant story for a long time, it's true.

Jones: That's true for the leadership, but it's not true for the people who are trying to get a job. It's not true for the people who are trying to get an education for their disabled child. It's not true for people who are just trying to live their life. It's true for those who are in this movement, who are pushing the envelope. Some people wrote to us and said, "All you ever talk about is the ADA." So we kind of had to back off a little bit because we didn't want to lose those people. We needed them. We needed every person we could get. So we kind of backed off a little, but not a lot. We backpedaled a little.

In 1990 we're coming up on the ADA. I can't remember why I was in Washington, but I went back and I was lobbying with Erica Jones, actually. I went to the meeting that they had. The meeting was with the core group--Paul Marchand--what's the group called? CCD [Consortium of Citizens with Disabilities]. I remember talking to one of the staffers at the judiciary committee. It was a woman. She came out and was talking to us. She said, "If we're in a small town and they have two stores, and one of them goes bankrupt because they have to make it accessible, then the town will only have one store. It will basically be a monopoly." I looked at the woman and I said, "If you have two stores in that small town and both of them are inaccessible, then I can't shop in either one." She hadn't thought about it. I don't contribute much to all of this stuff, but that was one of the things I did. I feel like she got it. One by one you get it. I remember feeling pretty good. I just had the right thing to say, and you oftentimes don't have the exact right thing, but that was the right thing. All of a sudden it was like an "Aha!" experience for that lady. I felt pretty good about that one.

During this time period we're working trying to keep people calling and sending letters. E-mail wasn't so much a big deal then; it wasn't there yet, at least that I know of. People were writing letters. Any time they wound up in Washington they were doing lobbying. This was a real nickel-and-dime thing. You think of the poorest population trying to do this work. The poorest of the poor weren't the ones doing the work. It was the people who really weren't the poorest of the poor in terms of the disability movement; it was the people who had jobs, who really--in a lot of ways you can get by. It was a wonderful thing going on.

There was a lot of sacrifice going on. I remember Diane Coleman: she sold her house in Los Angeles, which was a high-priced market, and she went to somewhere in Nowheresville, Tennessee, and spent that money doing advocacy work. She spent the money from her house doing advocacy work. Same thing with Mark Johnson. Mark Johnson sold his house in Denver, Colorado, and went to Alpharetta, Georgia, and was able to do advocacy for like two years on the differential in the housing market. I say those things because I guess for posterity people need to understand that people sacrificed a lot to do this. You probably have tons of other stories of what people gave up and sold and did.

I think that people need to understand that for Diane Coleman and Mark Johnson, they were the few that owned a house. Most people didn't own a house. You don't have a job because you don't have accessible transportation, and you can't get a job anyway because you're not educated because you had this stupid special education that didn't teach you nothing. You couldn't get a group of people to demonstrate because you could only get two people in your van if you're lucky. How do you get a hundred people to a demonstration site? You can't. You can, but it's really complicated. So I think that the organizing was really grassroots, and that's also the reason why a lot of times the media didn't see the movement. You couldn't see it. You couldn't get people in one location to be the movement, so people were primarily calling and writing.

Justin, of course, went around to all the states and was accumulating stories of ADA and discrimination. One of the things we had to do was educate people that they were discriminated against. It's like "You've been down so long it looks like up to me." People forget that they should expect to go in the front door of a business. They forget that they should be able to go to the bathroom in a restaurant. You've been using alternative means of getting the job done for so long that you forget that you should be treated like everybody else. So a lot of that education was not just accumulating in stories, but educating people what constituted discrimination. That was all going on during that time frame.

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Breslin: I was trying to ask you earlier about the relationship, if any, that you think you and Mainstream had with the Berkeley/northern California/Bay Area disability movement. Or people from the movement here. If there was any relationship, did it influence you in any way?

Jones: Back when Mainstream was first started, of course Ed Roberts came in. He was head of DVR, and he helped get some of the initial funding for the magazine. He also came down and visited the site. Basically, it was that connection. It was just a personal connection. We listened to him tell stories, and he listened to us. You think of the head of--I think that was important.

I came up to Berkeley to visit a friend, and I went to the Center for Independent Living [CIL], and that was in '77. He was an architectural grad student at Berkeley. I went down to visit CIL and I met Michael Winter, who I think was the director there at that time. I can't remember the players. Was Bob Funk there in '77, and then he started DREDF?

Breslin: Summer of '77, fall of '78.

Jones: That probably is where I met Bob Funk. Then he went to DREDF, and then we had a relationship in the very early years with DREDF, and Bob wrote some stuff for us and that was part of how I got connected there.

We came up in '87 for the ADAPT/APTA demonstration. It was at the Hilton downtown, and it was all torn up. That was a mess. We knew people and we could call them.

Meeting with President Bush on ADA Remedies

Breslin: The ADA is enacted--

Jones: Actually I'm going to go before the ADA is enacted. We talked a little bit about this last night--this was a painful experience. I was invited to the meeting with George Bush. The question is the question of today: remedies. Except I didn't quite comprehend how important this question was. But Liz Savage tried to tell me how important this question was, and I tried to pay attention. She briefed me.

What happened was the White House calls and says, "Can you come and meet with President Bush?" My secretary thought it was a joke. She said, "Who is this really?" You don't get a call from the White House every day. The person said, "No, this is really the White House, and we're having a meeting on May 1. Can Cyndi Jones come?" By the way, there's no money and you've got to pay your own way--they don't say this--we haven't given you two weeks' notice, and it's in the middle of the week so there's no Saturday night stayover possible. That means that it's the

most expensive airline ticket that you can possibly buy [laughs]. None of us in the disability movement ever plan anything that way.

We're at 1990, there's a recession going on, our ad revenues are dropping--not just at Mainstream, but across the board magazines were dying. I'm thinking, "Do I want to spend \$1200 to go to Washington, D.C., to meet with the president?" That's the choice.

In the meantime I start getting calls from everybody in the universe telling me what the question should be that I should ask [chuckles]. You should ask this, you should ask that. Everybody's telling me what they think I should ask. I'm trying to think if I should spend the money and go. Liz Savage calls me and says--I was coming in whatever night it was, and she was going to meet me for dinner and brief me on this question. She explains remedies and how it's a problem and we have to get this straightened out, and we have to nail Bush on this because otherwise there won't be any remedies in the act, which is the problem we have today.

Breslin: And what did she explain to you remedies were about?

Jones: That you wouldn't have any damages. In other words, someone who sued would not be able to get monetary damages. You could still get your attorney fees, but people wouldn't get paid any damages. But I didn't really comprehend how serious a problem this was. I thought if attorneys are going to get paid, we're going to get suits out there. But I didn't really understand how important this was. But fine--I can do that. Then I'm sitting in my room thinking, "I don't know who else is going to be at this meeting. I don't know who's going to ask what questions. I'd better come up with another question, because what if that question is already asked? So I sit down and I write out two questions. I have the remedies question, and I have what turned out to be the question I asked.

When we go in, my scooter starts malfunctioning big time. I can't turn it. I took my scooter in a cab. When the cab driver pulled my scooter out he did something. I don't know what he did. I couldn't steer the thing; I could only go straight [laughs]. It's about a twenty-foot turning radius [laughter].

Breslin: A big circle.

Jones: It was kind of a problem. Then the people come in and say, "Are you going to use your scooter when you go talk to Bush?" I said, "Well, I didn't bring my crutches, so yes. Or I could stand and

walk, but I'm not going to walk very far." They weren't trying to tell me what to do, they just wanted to know. I guess what the answer was, if I was going to be not in my scooter I would have sat next to Bush. But because I was going to be in my scooter they didn't want me right next to him in case there was some bomb or something. I don't know. But I know there was some discussion about the seating arrangement, and it had to do with whether or not I was going to use my scooter.

I go in there and they have it arranged where Bush sits in the middle of the table. It's an oblong table. So he's not at the head of the table; he's in the middle. Next to him is Cliff Crase from Paraplegic News. I could go around the circle but I can't remember everybody who was there. Around the table were about twelve people. On his left was Cliff Crase, and on his right was the woman from Disability Programs and Reports. And then there was me, and I can't remember who else. Joe Shapiro was, in the asking of the questions, maybe eighth or ninth. There was also Nolan Crabb with one of the blind newspapers. Ray Cheever was there from Accent On Living.

Breslin: This was basically a press meeting then.

Jones: Only a press meeting. What happens is it goes around and someone asks the remedies questions. Bush says, "I'm not answering that. I'm still thinking about it. We're not going to discuss that today." Ray Cheever was next to ask. Oh, my God, I was so embarrassed. His question to the president of the United States was, "How do I get on the White House mailing list?" [laughter] I couldn't believe it; I was mortified. I wanted to crawl under the table. Then someone else on the other side asked the remedies question a second time. Bush said, "I've already said I'm not going to go there. We're not going to discuss remedies." Then someone else asked a question about the braille. "What are we going to do about how the blind students are not learning braille?" There was a deaf question from someone. Joe Shapiro asked a question about the [Larry] McAfee case. McAfee at that point was wanting to commit suicide, and Joe wanted some intervention with Georgia regarding Medicaid waivers.

Let me go back one second: this table had all the people around it, and then there's like a little walking space, and then there's a whole set of chairs around that. So it's like a donut. Bush is looking straight across to one of his people and he tells someone to get on that. So actually Joe's question about McAfee has an immediate effect and gets some action so that McAfee can get out of the nursing home. So that was positive.

Then someone else next asked the remedies question for the third time. Bush is getting a little pissed. He's really getting irritated. He says, "I told you we're not going to talk about that." I decided not to do the remedies question.

Breslin: That was a good decision [laughter].

Jones: It's just going to piss him off. He's not going to answer it anyway. So I ask another question. I asked the question that has actually become the IOM [Institute of Medicine] report. The question was--I started talking about how, "Mr. President, you have a lot of power. You speak and things happen." Kind of get into his Episcopalian background. See, I knew he was Episcopalian, so I could tap into his religious history. Kind of like the word goes forth and creates. I said, "The people we represent sometimes can't even get out of bed in the morning because they need attendant services. They try to get a job and they fall between the cracks because of SSI [Supplemental Security Income] regulations. They try to get housing, and Section 8 has problems. There are all these gaps in the programs, and what we need is--" he said, "Kind of one-stop shopping." I said yes. He said, "I'm not that powerful. But I can fire up some of my assistants to find out what's happening." So as a result of that question he asked all of the departments, I guess, to say what their programs with disability were and how they interface. That question became the IOM report.

It was funny--kind of fast forwarding. I was on a board at NIH [National Institutes of Health] called National Center for Medical Rehabilitation Research. I got this three-inch-thick notebook and I start reading it. I mean, I didn't know anything happened to that question. I asked that question and he said, "I can ask the question. I'm only the president, and this is a big bureaucracy." Of course those of us know that that's true, but he does have power. So I'm sitting in this meeting years later and lo and behold I start reading this report, and it's the answer to that question. It was nice.

Then the woman from Disability Programs and Reports asked her question, and I cannot remember what it was. Memorable that it was, I guess. That was the end of the thing. He shook everybody's hand, and then we left. And my scooter was still not having any steering ability [laughs].

Joe Shapiro said, "Do you want to go grab something to eat?" I said, "Sure, but you have to be aware that I can't steer this thing." I didn't know what the problem was. So then I go back to the hotel thinking, "If I get to the hotel I can take this thing apart and see if I can figure out what the problem was." I

get back to the hotel and take it apart, tip it upside down, and I can see that the guy had just turned the wheel around backwards. He had done a 360 and there was no more give in the wheel.

The story is if Liz Savage tells you to do something you're supposed to do it. She was pissed that I hadn't asked the remedies question. She didn't want to hear about it. Fine, don't hear about it. There was just a ton of grief over not getting the remedies question asked or answered. It was asked.

Breslin: It's not that it wasn't asked, after all.

Jones: It was just not answered. That's haunted me, because right now we're dealing with that question. This is where we are right now. Not the answer to it but the fact that there aren't any remedies in the ADA.

Breslin: Well, there are. It's only Title III that's problematic, and you couldn't have fixed it in that meeting.

Jones: That was May 1. Then we all came back for the signing on July 26. It does pass.

Breslin: Right. It passed the House, but the Senate vote hadn't happened at that point. Is that where it was?

Jones: No, it hadn't passed the House at that point either. Did it? When did it pass the House?

Breslin: I can't remember.

Jones: I don't think it passed either. But it was about to. Bush was so smart: he knew that all the disability press were monthlies. So he knew that in order to get in our July issues, he had to have this meeting in May. It was all timed.

Breslin: Don't give Bush that much credit.

Jones: Kind of. He knew he couldn't have it in July or none of us would have anything in it until December--not quite, but close.

It passed the House. I went to one of the meetings--I think it was Judiciary. I went over and watched. This whole stuff about AIDS, HIV. If you sat in that room you knew that they knew that that's what they were talking about. That's what they were talking about. "If a person who's in food processing cuts their finger and the blood drips on the salad"--okay. That's the

discussion we were talking about for like three hours in the Judiciary Committee. Maybe it was two hours. It was a long time. Now [1999] that we're talking about the Bragdon case, anybody who would listen to any of the discussion knew that everybody knew that that was covered. It got passed through that committee and it went on. Everybody knew. There was no doubt.

ADA Signing Ceremony at White House, 1990

Jones: Then it passed the Senate. Then they planned this party. I guess Justin was involved in that. I think he had Peg Nosek come in and start making phone calls. There were a lot of people to call. This was the biggest signing of any act [chuckles] I think in history. More people were there. It was 3,000 people on the lawn, it was all the Supreme Court and most of the House and Senate. Anybody who was anybody and all the advocates. All the advocates--there were a lot of wonderful stories about that too. People who had begged money and stood on a street corner with a tin cup in their hand getting money so they could come to the signing. It was an amazing thing.

Breslin: Did you and Bill both go?

Jones: No.

Breslin: Just you?

Jones: Yes. Bill was still working at the UT [Union Tribune]. He wasn't invited.

Breslin: Was it important for you to be there?

Jones: Yes.

Breslin: Why?

Jones: I don't know. It's really historical. I sat there on the lawn, and it was a warm summer morning in Washington. All of a sudden there was this breeze that went across the gathered assembly. It was kind of like a new breath of air was sweeping across America. I felt it. I thought it was kind of symbolic. The wind was starting in Washington and was going to blow across the whole U.S. and change the face of America. It hasn't really happened so much now. But it was important to be there.

Breslin: What was Mainstream's direction after the ADA was passed?

Jones: The battle cry before the ADA was "No weakening amendments." Send your letters, write your congressmen: no weakening amendments. So after the ADA was passed it was enforcement. But we had a little bit of time in there before it really started being enforced because the regulations had to come out. But they were kind of pro forma. It was the 504 regs that were reworked a little bit and came out. Then we started talking about enforcement and trying to get people to understand that they had these new rights. People didn't even know. Even today only 47 percent, I think, of Americans with disabilities know that they're covered under the ADA--that they even know there is an ADA. So we started trying to tell people what their rights were. We spent a lot of space in the magazine--well, you wrote some of this, Mary Lou. You did pieces on transportation, on public accommodations and Title I, Title II, Title III. We ran information about what the act meant. Not necessarily the act verbatim, but what it meant. We tried to get people to understand that they had rights.

An interesting thing happened when we went to different places after that. I'm talking about trade shows, not advocacy things. People started claiming their disability. People who before would never have said "I have a disability" would say they have a disability. There was an amazing change that happened that is subtle but it was very real. I knew that you could never stuff it back in a bottle. You could never do it. People knew they had rights. That was wonderful. It was a wonderful change that happened.

Then we were doing the enforcement stuff, and we started writing about how people had to start pushing on enforcement after the regulations came out because without enforcement the ADA was not worth anything. The way that ADA gets enforced is by people complaining. So first of all you say, "Write to DOJ [Department of Justice] or EEOC [Equal Employment Opportunity Commission], write your letters of complaints," trying to get people to generate complaints. I don't think that was real effective. I don't think people have complained as much as they should. It's hard to complain; you don't want to be a whiner. Besides all these people who are used to making things happen for themselves, now they have to say, "Oh, I can't do this." Nobody wants to say what they can't do; you want to say what you can do. So it's kind of contrary to the whole disability culture in a way to complain about things that make your life hard. It's kind of opposite to the way we've always lived our lives, and now we have to turn it around and tell people to complain about what makes it hard for them.

ADA Lawsuit in San Diego

Jones: We tried to get people to file lawsuits.

Breslin: Through the magazine?

Jones: Yes. We told people to file lawsuits. It was five years after the ADA, 1995, and by all accounts we should have seen some voluntary compliance by then. We had some voluntary compliance, but we had not nearly enough compliance. It was our twentieth anniversary issue and I said, "In our tenth anniversary issue we talked about 504 not being complied with and send in your complaints, and now on our twentieth anniversary we're talking about ADA. If we don't file lawsuits today, the children of today will have to file lawsuits on the next piece of legislation twenty years from now." We have to realize that the way this thing gets done is through either complaints or litigation or some kind of street action. I said, "If you're not going to file a lawsuit for yourself, file a lawsuit for the kindergartner with a disability, because whatever you don't do will be left to him." We have to do this.

As a piece of that, Bill and I filed a lawsuit. Actually, do you want to hear this story?

Breslin: Acting on your own advice.

Jones: What happened was people in San Diego organized, and we formed a group called the Firm. The Firm was non-incorporated; it was just a group of people that were the activists in San Diego. There were maybe eight to ten people. We sat around for several months--once a month or so we met--and we talked about the problems and what we were going to do about them. We knew that we wanted to have lawsuits that were quality lawsuits. We didn't want them to be just nickel and dime stuff. We were kind of looking for targets. We wanted good cases. We knew that we could win on parking, because parking was easy. If somebody hadn't painted a blue space, that was easy and it was readily achievable, and there's no reason that they shouldn't have done it by now because it's five years after the ADA and three years after the compliance period.

Disabled Underrepresented in Media, 1993

Jones: Let me go back a few years here. In '93 I was invited to participate in a conference in D.C. called New Directions for News at the Freedom Forum. Freedom Forum is basically the news foundation; it's really the First Amendment foundation in the U.S. They were doing this study on underrepresented groups in the media. This was in '93, and I was invited to participate. What happened was they asked me if I wanted to come, and they sent me a stack of homework to do before I came. The homework was I had to go interview an African American businessman. I was supposed to--which I did not do--attend an African American church service. They got me this stuff so late that I didn't have time to do a Sunday service. I was supposed to read the newspaper and chart for a week the coverage on African Americans in the newspaper, from front to back. I did those things. I was also supposed to get the census data on San Diego, on what the percentages were of African Americans in San Diego and education --the whole census tract stuff. I got that done too.

So on top of doing all the magazine stuff, I'm doing this homework. I thought, "This is interesting; I'm learning a lot about this. It's good for me to do this." I'm wondering who's doing this stuff on disability; that would be really interesting to find. Nobody. Nobody. Disability was so underrepresented that it wasn't represented on underrepresented. I was so hurt. I thought, "Here we've passed this major piece of civil rights legislation and the media still doesn't even see us. People who are studying non-coverage don't even know enough about us to cover us as non-covered. I was crushed. God, what do we have to do to become underrepresented? [laughs]

That was a real hard conference for me, but it was a real eye-opener as far as the media problem that we have in the movement. That was '93. I was devastated. They covered women, children, teens, people of color and ethnicity, and older Americans. So basically the only ones they were figuring had enough coverage were white males in middle age. Middle-aged white males had enough coverage [chuckles]. That was kind of a shocking experience.

Then I did a cultural diversity thing I was invited to at the city of San Diego. It was the top echelon of people. It was the chief administrative officer of the county of San Diego, it was the chief of police, the sheriff--I'm not talking about the assistant, I mean the sheriff. It was not the mayor but the mayor's first in command. There were fifty people there and it was all this top echelon of people in the city. There was a pre-

meeting you had to go to the week before this workshop that was three days. It was in a room and there was a big conference table and chairs. There was not a seat at one place and I thought, "Oh, that's nice. They knew I was coming and they pulled a chair away." Wrong. The guy said, "That's where I sit." He was leading the discussion. It was the head of the table. How was I supposed to know? I said, "What you have to understand is that I sit where the chair isn't."

We're talking, and all of a sudden--I have to say it's an African-American cultural diversity firm. Kahlil Jameson is the name, by the way. By the end of this pre-meeting he tells me, "You can't do this by yourself; you have to bring another person. You need at least two people in any minority group to be represented in this cultural diversity training just by the way training happens. Go find yourself a partner and have them come." I guess that's why they do this pre-meeting; so they can make sure there's some balance and support. I go home and say, "Bill, do you want to do this?" He didn't think that we could afford to have both of us go to a three-day meeting. By the way, we skipped that part, but Bill came on the staff in '92, and we'll come back to that.

I call Patricia Yaeger, who is the head of the Independent Living Center in San Diego, the access center. She had just come to San Diego, but I had met her before. Maybe she had been there six months or a year--not very long. I asked her if she'd like to come with me to this training. It worked out perfectly for her because it gave her a very high profile in the city, and she was new to the city, and she got to meet all the players. It was a real eye-opener at that meeting. We learned a lot about disability culture even though that wasn't really on the table. Each group broke off and talked among themselves; that's why he said you had to have a partner, because you can't talk to yourself. One question was, "What do you need from the other groups?" After we thought about it a lot, we thought we need them to raise their expectations of us. It was an important meeting for me personally, but for her it was good because she learned all the players. We actually had an entrée to the chief administrative officer of the county. We knew the people by name and they knew us, so it gave us entrée to high places.

Bill came on the staff in February '92. What happened was the San Diego Union Tribune, which was a morning paper and an afternoon paper, merged. Because he was management he could take the buyout. He took what amounted to fourteen months of pay and quit his job. That money went into the magazine. Ta-da! Going without a net [laughs].

Breslin: Did he lose retirement?

Jones: No. He was vested in his retirement. But we did start taking the retirement money, because when he turned fifty-five he was eligible to take early retirement and we needed the money.

After this diversity meeting with the city, we were planning the first DID [Disability Independence Day], and we made an announcement about that. Every year after the ADA, San Diego always had what we called Disability Independence Day. It's around July 26, we invite everybody, there's food and entertainment, there's a speaker. It's a good time. The people said, "Oh, that's when the Gay Pride Parade is." Well, that's a whole other story; I can't go there now. They moved their date on to our date and all of a sudden there was a big conflict. We're small, we should move. No, this is our day, you should move; you moved onto our date. It's caused a lot of conflict, and a lot of energy that didn't need to be spent.

The Firm Opposes ADA as Local Option

Jones: Then this group formed, the Firm. What happened was Newt Gingrich was coming into power, and he wanted what's called a Corrections Day in Congress. He got Susan Golding, the mayor of San Diego, who was like the heir apparent in the Republican party, to ask the city to pass a resolution to make the ADA a local option. The city of San Diego was going to pass a resolution to make ADA a local option. Well, we found out about this on Thursday night, the city council meeting was on Monday, and this was on the consent agenda. That weekend we wrote position papers, we got the packets together, we put all the information together, we delivered the packets to the city council members and their staff members, and we turned out thirty-five people on Monday morning for the meeting.

They were shocked. First of all, we weren't supposed to know about this; it was supposed to be just slid through. We were successful: we got them to back down. They couldn't stare us in the face and vote ADA to be a local option. Now had they done that, it would have been an interesting thing to have happen to go to Congress. But we were just as glad not to have that go to Congress. At that time, the Republicans with their new agenda were running strong--their Contract with America--and they were pretty powerful at that point.

Entree to City and County Officials

Jones: We formed this group called the Firm when we realized we--the ADA--were really under attack. Instead of being on the defensive we've got to be proactive on this. We started looking for targets. We didn't want to spend our energy on nickel and dime stuff; we really wanted it to be good stuff. This parking case came up, and meanwhile the county was not in compliance. They started a task force at the Independent Living Center on the county's non-compliance. They were working on that and working on that and getting it all tied together. Meanwhile we went out one day--there were eight of us--we divided into groups of two, and we surveyed a hundred parking lots in the downtown city of San Diego. We divided the city into quadrants, and each group was to survey either northwest, southwest, whatever. There was like a hundred parking lots. I don't think we did all of them that day, but we did like forty-six of them. You had to count the number of spaces, and you had to see how many blue spaces there were. The blue spaces were easy; the harder part was counting how many spaces were actually in the lot. There were a couple of brand-new lots with new hotels that had access, but most of them had none.

We had this whole thing lined out, and we hired a law firm: Procopio, Savage, Corey and Hargraves. Our attorneys were Lynn Lazrey and Richard Valdez. They're both wonderful people. Lynn was nominated for a federal judgeship, but because of the Republican stuff they had her on hold for two years and she withdrew because she couldn't afford it. That happened the same time as our case. We talked about the case for a long time. We signed on Sid [Sidney] Wolinsky as a co-counsel because Richard and Lynn were not confident of their ADA skills, but they were interested in doing ADA law. We worked on it a long time. Then we were going to file the suit, but we were out of town. Then they were going to file the suit but they were out of town. We kind of went back and forth about filing this lawsuit.

We planned the media coverage around it too, by the way. We knew that we wanted to file the lawsuit on a Tuesday, Wednesday, or Thursday because that would be the best media coverage. We filed the lawsuit and we went to a corner in downtown San Diego where it was a city block on one side and a city block on the other--it was all Ace Parking. There were no handicapped places on two full city blocks. It was like a slam dunk. The next day one of the TV channels who couldn't be there asked if they could come back to the place and do it today. We said sure. Well, by the next morning there was blue paint. The blue paint fairy had come. In some ways we won. I had really mixed emotions about

all this because it was the perfect case, and now it kind of undercut the lawsuit because they had actually started compliance immediately.

But the other thing was it made me mad. If it was that easy to do, why didn't they do it before? They were just waiting to be sued. That's all. That was their strategy. At least that's what I thought.

The other thing that was a miracle about that lawsuit was that Ace was the contractor for the city on parking. The stadium, sports arena, convention center, everywhere. We filed the suit on Wednesday, and their contract with the city was up for approval the following Monday. When you file a contract with the city you have to say that you're in compliance with all the laws. So this caused some grief, and that's why they did compliance so fast, I believe. They had to in order to show they were in good faith. It was kind of funny because they thought that we knew that their contract was up, and that's why we timed it that way. We didn't know nothing!

Breslin: It was just good luck.

Jones: It was very good luck. It just worked out very well. It gave a boost to the community to feel like they actually had some power. We always showed up for court appearances looking like business people, raising the image of disability, that "we're small business people too just like you, and we understand," the whole party line. It was interesting because the attorneys across from us were high-powered attorneys, and they were the attorneys for the stadium authority and the port [chuckles]. All the players in town. You have to understand that at the same time this was going on, San Diego was trying to do a substantial renovation of their stadium--like an \$87 million renovation. They had no line of sight, and basically their seating was poor. Every entity had problems, and so these were the attorneys for those different entities.

At one point we were in the lobby waiting for the magistrate. The attorney for the stadium authority turns to me and says, "How are we doing?" I said, "You have a little bit of work to do. You're lacking a few spaces." He said, "Parking?" I said, "No, seats." At that point, it was very interesting because he really wasn't looking me in the eye; he knew what the answer was. Just before that week or just after that week was all this stuff that hit the fan about the Olympic stadium in Atlanta. DOJ [Department of Justice] had issued a ruling about the stadium in Atlanta. So I had this fax from DOJ about line of sight, concession stands, et cetera. Four pages. I faxed that

over to Mr. John Wertz, the attorney for Ace Parking and a member of the stadium authority. I highlighted the pieces. I said, "I think you have some work to do." I wasn't being mean or nasty, I was just giving him the information. He could've gotten it from the Department of Justice; it was public knowledge.

This lawsuit gave us entrée at a different level as well. It also meant that some of these people who were the lawyers in positions of power understood that they could have formidable opposition. It was a real positive experience. When the stadium was being renovated, the Citizens' Review Committee [CRC] was not as strong as they should be. Maybe they gave away a little more than they should have given away in the negotiations. But Ace Parking was the contractor for the parking lot at the stadium, and they had agreed in our settlement that they would bring the stadium parking into compliance. But the CRC had given away a little of that in their negotiations. So we're at a compliance meeting and they're talking about the stadium and all of a sudden I said, "Well, didn't you agree to bring the stadium parking into compliance?" Oh, man. They said, "Oh, we were talking to the CRC." I said, "I think you're under court order." They were. God, I felt good. Because we had a lawsuit--actually that was the settlement: they had to bring their parking into compliance, and that was one of their parking lots. It gave us power that we wouldn't have otherwise had. That was real positive.

Paralympics in Atlanta, Georgia, 1996

Jones: The county suit is still in litigation. We're about ready to do some other stuff. I think it helps having a group be able to do some stuff that is not nickel and dime but high-profile and puts you in a position to work through.

Breslin: What's happening with the magazine in the mid- to late nineties?

Jones: We're working our butts off. We're finishing up this lawsuit with Ace. Actually it had been filed.

##

Jones: In the early nineties the Olympics are coming to Atlanta. It comes off a real high in Barcelona. They did a great job on the Paralympics, following up on the Barcelona Olympics. The U.S. Olympic Committee are being jerks. First of all they tell the Paralympic Committee that they can't solicit any sponsors that are not Olympic sponsors. If Olympic sponsors don't want to be a

sponsor for the Paralympics they have the option to release their category or not release their category. That means that, for example, there were six companies that refused to sponsor the Paralympics that also didn't release their categories. That was Budweiser, Sara Lee, John Hancock, McDonald's, Visa--I'm going to miss the other one. Basically they're high-profile companies. The Paralympics couldn't solicit American Express, which wanted to sponsor. It cost Paralympics a lot of money. As we got closer to the Paralympics, they created this mascot called Blaze. You know, rising from the ashes. Then when it became a success the Olympic Committee wanted to own that as well. It's like, "What's ours is ours and what's yours is ours." It was really awful.

As it got closer to the Paralympics, what happened was they didn't have enough money and they started laying off people at the Paralympic Committee. Then they started making cuts in how many people could come from each country for the Paralympics and how many people could come for each sport. Pretty soon it was whittled down and whittled down. There were a lot of people who thought they had made the cut, and then three weeks before the Paralympics they hadn't made the cut. It was very awful.

Then when the Paralympics happened, the Olympic Committee had left the Athletes' Village a mess. They hadn't done the accommodations they were supposed to do; they had just left it. It was a mess. Olympic Park was dismantled before the Paralympics, which was like three weeks after the Olympics. Then they had the banners and all that stuff torn down. Everything was torn down. It was a mess. It was disrespectful and awful.

We were there at the opening of the Paralympics. We were credentialed in as press, only when we went to the press booth it was inaccessible. Then we went down the way and there were inaccessible seats at that press station. We kept going until we got to the end, and finally we got to the end and oh, there was this place for wheelchairs. It was great. Wrong! It was actually the place where the announcer for the whole event sits so that they have a very good seat so they can see what's going on. Just before the start of the ceremonies they wanted to move all of us. There were half a dozen of us in that little room that had finally found a place that we could be. They realized we were not moving. We hadn't really realized it was the announcer's booth until like about a third of the way through the thing, and then we realized it was the announcer who had actually moved the equipment. It was kind of fun.

It was a very long evening. All the athletes from around the world were there, and it was a wonderful camaraderie. I'm

not an athlete, but I kind of do this stuff on athletics and other groups because I feel like we need to bridge the different communities of the disability community. I don't think the activists do that very well. So this is like our outreach. It's been what we've done for a long time in little fits and starts. The floor of the stadium is filled with all the different costumes and colors. It really felt good.

Christopher Reeve Announcer

Jones: Then Christopher Reeve comes on, and he's the announcer. Oh, deadly. He talks about how if there was a cure then all of you could get up and walk.

Breslin: Oh, dear.

Jones: Oh, dear. It was awful. There was this silence on the field. Of course, he's newly injured. That was '96; he had been injured only eighteen months. There was a silence on the field because all these people had adjusted to their disabilities and who were actually performing well, doing well--

Breslin: Proud of their abilities.

Jones: Proud of their abilities. There was a silence on the field, but the stadium is all non-disabled people. They had given away tickets to schoolkids or whatever just to fill the stadium. It's all nondisabled people in the stadium, and the stadium erupts. The field was silent. It was just an incredible experience to be there.

The last thing they do is they light the torch. The torch comes in and it's one athlete and another and another. Scott Hollenbeck, who was a local Atlanta champion racer, goes around and up to the end--by now it was like eleven o'clock, we had been there all evening. Who's going to be the last person? They don't tell you in advance. Even on the press sheet, where they always tell you in advance all the stuff that's going to happen. The last person is not mentioned. The torch hands off to about six athletes in the stadium as it goes around, and it goes up the stadium steps. I think his last name's Dempsey; he's an African American jumper-amputee. There was Trish Zorn, who was a blind swimmer. It was all the disabilities. It was a very exciting event.

It hands off to Mark Wellman. He proceeds to climb the cauldron in his rock climbing stuff with the torch between his

feet--it had a torch holder. So he ascends this ninety-foot empty space, basically, to light the torch. It was exciting to be up in the press section. It's been a long night, the press people are tired, they're thinking "Oh, God, let's just get this sucker over with." All of a sudden you could see the energy: Mark Wellman is climbing this cauldron. It was amazing. Just the buzz--people were on their phones to their editor. You could hear them saying, "You won't believe what we're seeing." There was this excitement that went through the stadium. It's like making a silk purse out of a sow's ear. They did a great thing.

The reason they chose Mark Wellman, it turns out, was it was a political statement about inaccessibility. What they were saying is that you have to be a fucking rock climber to get around in America.

Breslin: You might have interpreted it that way--

Jones: That's why they chose him. They chose him because there was no other way for anybody to get up there to light it. They wanted to make a political statement about inaccessibility. That's what Mark Johnson said from Atlanta.

Breslin: He may have put a good spin on it--

Jones: But that's not it?

Breslin: I really don't know. I'm just too cynical in my old age.

Jones: At any rate, it was wonderful. It was fun being at the Paralympics. What happened leading up to the Paralympics was that Sunrise Medical was spending a lot of money. They put in--I think it was two million dollars. They were the initial sponsor of the Paralympics. Other people were putting in money and Invacare was not a sponsor because they only have one per category, and Sunrise had bought that. So Invacare was spending money in our magazine, a significant amount of money, for two-page spreads and color and stuff, trying to offset the thing that was happening with Sunrise.

Media Sponsor for Paralympics

Jones: The Paralympic Committee had sent us a proposal to be a media sponsor along with everybody else. What they actually asked us for was what amounted to \$250,000 in media space over a two-year period. I thought, "For what? For the opportunity to go to the

Paralympics. To buy tickets. That was basically it." People were so arrogant that they didn't know the media, and then they added insult to injury because they said--I can't remember what magazine this was, and they don't even exist anymore--it was like, "So-and-so has signed on. Why don't you?" I'm thinking, so-and-so isn't a real magazine. They said they had so much circulation and they really didn't have it. I said they're probably not even going to be around when the Paralympics happens, and actually that was the truth. They weren't around when the Paralympics happened.

I went to Atlanta, and the president's committee was meeting in Atlanta that year. I guess it was maybe '94. I said to them, "Why don't you do this? Why don't you print like a four-page insert? If you send that to all of us, everybody would insert it for you." But for us to print four pages every issue, you're asking a lot. For us to insert four pages, gosh, I could do that. Well, Marilyn Hamilton, I saw her at the DREDF event in Washington, D.C. Wasn't it in '94 that they had that? I told her, "I was talking to the people at the Paralympics, and I think that they should just send out an insert and we'll all insert it for you." She looked at me and said--if looks could kill--"Everybody doesn't want to be in all the magazines."

Basically what she's saying is that Sunrise doesn't want to be in Mainstream. That was the message. She's a Sunrise person. It was a good idea, and I was willing. An insert, we charge \$1000 a page for an insert. So I basically was saying I'd give them \$80,000. She just threw it away. I told them that they should send us little slips and we'll stuff them in all of the mail we mail out. We mail out like 6,000 pieces a month. That's 60,000 pieces for two years.

Breslin: Why do you think that she wasn't interested in advertising in Mainstream?

Jones: I don't know. Because Sunrise wasn't advertising with Mainstream.

Breslin: Why not?

Jones: They hadn't been for a long time. I think we're not glitzy enough. They were pretty much spending their money with New Mobility at the time. We're not 100 percent wheelchair, which New Mobility is. We also do a lot of blind. Kathy Wolfe has done a lot of writing for us and she's visually impaired. We've done a lot of stuff on aug com [augmentative communications] speech issues. They're not interested in those.

Breslin: It's too cross-disability for them.

Jones: Yes. But for whatever reason--it wouldn't have cost them anything to do that, almost. They would have gotten a lot of publicity, and they chose not to do it. I look back and think, "God, I gave them some really good ideas that they just threw away." They didn't get any other publicity either; nobody ran their stuff. They wanted more than people could give them. It's like going to someone who's on SSI and saying, "Write me a check for twenty-five dollars." If you're going to someone who has a job and making \$60,000 a year and you say, "Write me a check for twenty-five dollars," that's nothing. The people that they had working in the media part of the Paralympics had no comprehension--

Breslin: You're not the New Yorker.

Jones: We're not the New Yorker, we're not Sports Illustrated. And not just us; I'm talking about Paraplegic News, Sports and Spokes, Accent on Living. Enable wasn't in existence then, and We wasn't in existence then. They asked for more than anyone could deliver, and what we offered to give them they didn't want. Like I said, I was willing to stuff fliers in all of my mailing for two years. That's a lot. They weren't interested. That's okay, but I thought it was a bad strategy. If someone offers you something, unless you really can't do it, it just seemed weird because they didn't wind up getting any space anywhere else. They didn't sell the program, and that hurt them a lot as far as publicity and raising money. They were doing these things on sponsorships like for UPS or whatever, where they would guarantee them so many inserts in certain publications. Well, nobody was buying. We weren't buying. So it was kind of a problem for them.

So we went to the opening of the games, and we kind of got caught up in it. We wound up watching Tony Volpentez set the record for the 100-yard dash. He's a double amputee. Actually a quadruple amputee. He was born with birth defects. I think he was like four-tenths of a second off the world record off of a Canadian, Donovan Bailey. Then you have the kid from the U.S., what's her name? She's thirteen and cleaned everybody's clock. It was fun. We went out and watched ping-pong. Stuff you never do. We watched the U.S. men's basketball, and I can't remember who they were playing but they lost. It was fun watching some of this stuff. We watched some of the track and field.

Mainstream Ceases Publication, 1999

Breslin: What was the implication of the advertising issue with respect to the magazine?

Jones: When Sunrise had spent a lot of money on the Paralympics, and it didn't produce enough response--they weren't advertising with us; they were a Paralympic sponsor. The Paralympics didn't get as much media coverage. They didn't get national news coverage. We did an analysis, and the Paralympics only got 700 news stories across the U.S. The U.S. Olympics got something like 20,000. That was the difference. So they didn't get the bang for the buck, and that cost them because when you spend money on advertising you expect a certain response. So then the next year following that--and it wasn't just for Sunrise; it was for Invacare--all of the sponsors got shafted on the Paralympics. The only thing they should have thought of when they were sponsoring the Paralympics was "this was a good deed." Of course sponsorships and stuff like that isn't really for being a good deed anymore, it's for a return on investment that you think will happen in other ways.

Following the Paralympics, a lot of the companies had been pulling back on their advertising because they had overspent in '96. So now in '97 they were really doing a contraction, mainly to catch up. We kind of expected they would come back on line in '98. So '97 was a slim year. Then the other thing that was happening simultaneously--and I couldn't tell you what the exact date was, all the stuff on affirmative action.

Breslin: The California initiatives?

Jones: Yes, and actually across the country. Affirmative action was getting a little cold. As a result, a lot of our EEO advertisers were drying up because they thought they didn't have to do it anymore, so they quit advertising. We had a couple of them that continued that were very small ads like a quarter of a page or a twelfth of a page, but basically the large four-color or two-color had dried up. They disappeared. I don't want to say we were dying in '97, but it was a very hard year because your expenses go up, you have inflation, and also we started having other competition. Enable came out and We came out. Handicapped Postcards was doing quarterlies, card decks, and they had Abilities Expos doing five shows a year. We're expected to be at all those shows, and also because they're an advertising vehicle they were taking revenue from us. So there was a lot of competition. Some of what we'd call our mainstay advertisers were holding back trying to catch up after the Paralympics, our

AA [affirmative action] advertisers were not advertising because they didn't feel the need to anymore.

Breslin: That's your EEO--

Jones: EEO ads.

Breslin: Businesses advertising that they're equal employment opportunity.

Jones: Right. They're companies who advertise that they're an equal opportunity employer. Sometimes they do special ads for people with disabilities, and sometimes they just run their generic diversity ad. A lot of times it's not even for a job that's available. All they really want to tell you is, "Call us and we'll listen. Try us, we're open." Actually they can't run ads for specific placements because by the time the magazine comes out--it's a long time; it's like a three-month lead period. So basically all they can do is image ads. We used to have like four-color ads from Federal Express, Tennessee Valley Authority, Lockheed, McDonnell-Douglas, Boeing. Lots of big ads. Lots of those companies have merged. Mergers and acquisitions.

So a lot of the equal opportunity ads were drying up because they no longer felt the federal pressure for them to advertise. The Paralympics had created a position where some of the advertisers had overspent in '96 and hadn't gotten a return on their investment. Vendors of DME [durable medical equipment] equipment had been squeezed very tightly by the HMO [health maintenance organization] market. A lot of the HMO's were doing internal stores and cutting the profit to the bone. So now the advertisers who would be advertising, say, wheelchairs and cushions and things like that were really limiting their advertising, and only advertising in vehicles like Case Manager Review and case manager books and OT [occupational therapy] books and things like that. The consumers never really did exert control. They never claimed the power they had, so as a result they weren't a force so advertisers felt that they didn't have to advertise to them. So they quit advertising to them.

So there was contraction because of HMO's and that kind of marketing. We tried to get more subscribers, but it's really hard and it's very slow and it's very expensive. For every subscriber you figure it costs you about sixty dollars to get a subscriber and then they're going to pay twenty-four dollars. So the minimum is it takes you three years of a subscriber before you even break even with them. The main reason of doing subscribers is so that you have your ad base for advertisers. But the advertisers weren't happening anymore.

In '97 at first we just thought it was a slowing process and it would come back in '98. But the beginning of '98 we realized things were really bad. We did a story in March on Justin Dart. It was like sixteen pages. That was the real expense. We wanted to do that issue. I think at that point I knew things were very tight. We never should have run that issue; we should have quit in February. But we promised him. Then I thought, "Well, we'll see how it goes." So the next issue, April, was okay. May was okay, and June was okay, but they weren't profitable; they broke even. But then you get to July, and we don't have a July issue. Then it was just pure cost.

NIDRR Grant for Center for an Accessible Society, 1999

Jones: What's happening is we're evaluating what we're going to do. In the meantime a grant came up that we saw on the Internet. Actually, I don't watch for it all the time, and I guess they had been up there for a while because when we saw it it was June 25 and it was due July 10. We had two weeks. We had never written a grant before, we didn't have the pro forma stuff down, we didn't have any of the financial stuff. We didn't have our package anywhere near together. We had nothing. But it was a grant on dissemination of independent living research information. We thought we could do that because that's what we do. That's what we do anyway. We thought when we applied for the grant that it would help offset some of our expense with rent, and it would actually give Bill and me a salary, and we would offset some of the expense of some of our other staff members because they could do some of their time which was now vacant time, because we weren't having so many pages in the magazine. We could use part of their time, like 25 percent of their time, for the grant. That would offset some of their salary. It wasn't a lot of money that was going to offset for the magazine, but somewhere around \$20,000. But by the time the grant happened--we wrote the grant and were successful--we were losing too much money at that point that it was beyond the scope of anything that the grant would have ever done.

We wrote the grant, and it was for dissemination of independent living research through the mass media. So that's what we're going to do. We're going to work really hard to try to get the story out through the mass media, because we feel like that's the way you're going to have to meet people. The magazine worked for twenty-three years trying to get the message out, and I think we did a good job. I think that maybe we were ahead of the time. Maybe it's not time for a magazine for people with

disabilities for another five or ten years. The truth is people with disabilities still need information, and I think that we're going to do a good job. We felt this thing about how important it is for us to get the message out to people on disability rights. People who are disabled don't even comprehend what that is. They're not going to pick up Mainstream or they're not going to pick up New Mobility. They're not going to touch a magazine about disability; they're not going to claim their disability. But they still need that information. Maybe by disseminating information through the mass media we're going to be able to actually enlarge the movement and let people know that they do have rights.

Breslin: Terrific. So what do you see happening in the next five or ten years for you guys and in the movement? What's your vision down the road?

Jones: I'm hopeful that through the mass media project it should grow the movement if we do our job well. That's not what's in the grant, but we know that if people get connected that will happen. I think that the movement is in for some very serious times. I think that the Paralympics, and that time in the early nineties, I have to say looks like the height of the movement. I think we're on a downhill slope right now. Some very scary stuff is happening regarding euthanasia and the right to die movement. If we don't have the right to live, the rest doesn't matter. I don't see really as much organizing around that as I feel like there needs to be. We've been pushing on that since Elizabeth Bouvier--which was '83--we've been pushing against euthanasia issues. I think that advertisers are not going to come back to movement publications right now. I think that they can't afford it. I think they have to tighten their belts and go where it gives them the best bang for the buck, and I think that's going to be through case managers and that kind of thing. I think that we're not going to see them back for a long time.

I'm hopeful that we're going to win in the courts this summer. We just won on the IDEA case, and that was 7-2, and I think that was helpful. I think the movement needs a boost. It needs a positive lift, and I think that right now things are not looking so positive. I think most of the people in my generation or a little bit older are getting burned out and tired and have been at this forever. My God, we've been doing this forever. I don't see many replacements coming. I don't think we're growing the leadership. I don't think we're growing the youth into the movement. I think the youth think that they deserve all these rights and that they're not into trying to advocate for their rights; they think they already won their rights. I don't think they think that this stuff can be pulled away from them. So we

have a selling job for the disabled youth, too. The next decade's going to be interesting. I think it's scary.

I think that for us personally, not doing the magazine will be helpful. It was very exhausting. We've been working sixty-hour weeks forever. I can't remember a vacation. I was traveling like once a month, sometimes twice a month, and it's very exhausting, and you never get caught up and you basically have no life.

I think we look forward to this project. We have hope that we can actually effect change through changing public opinion. We have to change public opinion; we have to. Someone told me about--when we got awarded this NIDRR [National Institute on Disability and Rehabilitation Research] grant--"Just do the best you can," and I said, "You know what? We're going to exceed NIDRR's expectations." But if we fail, the movement is in for serious trouble. We really feel the need to succeed, and we feel the pressure of succeeding in this because the movement needs this to be successful. We need to change public opinion and move this agenda forward.

As we said at this meeting the last weekend about the courts, the courts can't do it all. We have to go back and backfill and bring the people along. I think we kind of jumped over that process of education, and now we have to go back and do that, not only bringing the nondisabled public along but we have to bring the disabled public along too. I have hope. I have hope that we're actually going to make this happen and move things forward. At least we're not going to be working--no, I won't say we're not going to be working sixty-hour weeks. You know how we are. It's hard to not; it's your life. What do you do if you're not working?

Breslin: Any last thoughts or comments for the record that you'd like to leave?

Jones: I think we've said it all.

Breslin: Cyndi, we forgot to put on the record the name of the new project that you're working on. Tell us what it is.

Jones: It's the Center for an Accessible Society. That's what we want, right? We want an accessible society.

Breslin: We certainly do.

There are a couple more things you'd like to say a few words about. One of them is about the incorporation--your decision

about whether to be a for-profit or a nonprofit organization--and about your niece who has a personal disability. So tell us about both of those.

Jones: When we incorporated and bought the magazine, the decision was whether we would be a nonprofit, which is what it was before and we could carry that forward, or whether we would become a for-profit. We felt that it was important to be a for-profit. Partly because people always view people with disabilities as a charity model, and we felt that it was important to say we're a real business and we're a for-profit just like everybody else. We strongly felt that that was the right thing to do. Having done that, like two weeks later, one of the large donors who was trying to empty his portfolio prior to his death, called us up and that's when you realize that maybe we made the wrong choice [laughs]. But that was the choice we made.

Breslin: This donor wanted to--

Jones: Oh, it was like four million dollars. We were no longer in a position to receive the money. That was the way it went. I wasn't in the psychological place to receive the money. We were ready to be a for-profit organization, and we weren't in a charity mode, and so that was the way that went down [laughs]. If he had called a month earlier--oh! Too bad. Life is life.

Breslin: It would have been a different course, and not necessarily a better one.

Jones: No. Different.

Niece Born with Down's Syndrome

Jones: Regarding my niece, Pamela. In May we got a call from my dad, and he was really distraught. He said that something bad had happened. Rae Jean was pregnant--my brother's wife--and he said the baby was born with Down's Syndrome. My dad and my mom were very devastated by this. There were a lot of issues around that, and I think it was partly because they knew--this sounds weird--how difficult my brother's life was going to be. I think they were thinking of their life. I think they felt sorry. They knew that Melvin's life was going to be different. It was a really fortunate time because normally we're so busy that we don't have any time. We're working forever and never have time.

For some reason, this was a time when we had a couple of days, so we went over to the hospital and we went into the neonatal unit. She was all hooked up on all these wires since day one. They didn't tell us we couldn't come in--I'm in my scooter and Bill's in his power chair, and we just wash our hands as if that's all you need to wash, and we zip into neonatal [chuckles]. There was Pamela, and we were talking to her, and she was doped up, I guess. She was there and really cute. We were talking to her and talking to Melvin. It was interesting how the staff in the hospital don't see adults with disabilities much. Probably in the neonatal ward they don't want anybody with disabilities because the other parents think, "Oh, my God, that could be my kid." But there was a real welcomeness to us coming in.

Melvin started on day two getting all this social service help--or not help. Bureaucracy is what he got. A week or so later he said to us, "You know, I never really knew what you did, and I don't know how you guys have done it for so long, but I appreciate what you've done." It was very powerful because--I guess the recognition. I guess that's what all of us do. We work and people don't even know what we did. All of a sudden they have this "Aha!" experience. It was a nice moment with Melvin.

Pam is doing fine. She had open heart surgery just before Thanksgiving. She's gained a lot of weight since the open heart surgery. Not overweight, but when they have heart problems when they're infants they just can't gain weight. She's doing really great. I think it's interesting because we're treating her like a kid.

Breslin: She's thriving.

Jones: She's thriving and she's doing well. Sometimes I wonder how much of the mental retardation do Down's kids have, because people don't treat them like they can learn. They treat them like they can't learn, so then they don't talk to them. She's doing great. In a lot of ways we're looking at her in the crib there and it's kind of like a generational thing.

Breslin: Yes, there's the next generation.

Jones: She's going to do great.

Breslin: She'll be happy to know her aunt when the time comes.

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Disability Rights and Independent Living Movement Oral History Series

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS

William Stothers

JOURNALIST AND MANAGING EDITOR FOR
MAINSTREAM MAGAZINE

An Interview Conducted by
Susan O'Hara
in
1999



William G. Stothers II, 1997.

TABLE OF CONTENTS--William Stothers

	INTERVIEW HISTORY	124
	BIOGRAPHICAL INFORMATION	125
I	POLIO AND EARLY CHILDHOOD IN REHABILITATION CENTERS AND MAINSTREAM	
	HIGH SCHOOL: THE LACK OF SOCIETAL EXPECTATIONS, 1940-1959	126
	Birth in Detroit, Michigan, 1940	126
	Family Move to Canada to Avoid Polio Epidemic	128
	Onset of Polio and Years in Rehabilitation Hospitals, 1950-1953	130
	Thistletown Rehabilitation Center for Two Years	132
	"Rowdy" Patients and "Sadistic" Hospital Staff	133
	Sister Kenny Hospital, 1952	138
	Warm Springs, Georgia, 1952	139
	Effects of Hospitalization	143
	Mainstream Public School, 1953	145
	Low Expectations and Parental Influences	147
	High School Valedictorian and Alcoholism	149
	Lack of Affinity for Other People with Disabilities	151
II	COLLEGE YEARS, EDITOR FOR THE <u>TORONTO STAR</u> , AWAKENING TO THE	
	INDEPENDENT LIVING MOVEMENT, AND A NEW OPENNESS TO PEOPLE WITH	
	DISABILITIES, 1959-1972	153
	University of Western Ontario Student, 1959	153
	Job with <u>Globe and Mail</u>	157
	UC Berkeley Student, 1966	162
	Personal Identity and Political Aspects of Berkeley	165
	Freedom of Power Wheelchair	168
	"Frightening" Cowell Hospital Program	170
	Canadian Editor at <u>Toronto Star</u> , 1968-1978	174
	Action League for Physically Handicapped Advancement	177
	Awareness of Independent Living, 1970	180
III	INDEPENDENT LIVING MOVEMENT IN THE UNITED STATES AND CANADA,	
	MEDIA DEPICTION OF PEOPLE WITH DISABILITIES, AND <u>MAINSTREAM</u>	
	MAGAZINE, 1977-1999	185
	Toronto Mayor's Task Force on Elderly and Disabled	185
	White House Conference on Handicapped Individuals, 1977	187
	Future Wife, Cynthia Jones	189
	More on Independent Living	191
	Ombudsman for the <u>San Diego Union</u> , 1978	193
	Media Coverage of People with Disabilities	195
	Increased Assertiveness	197
	Lectures on Disability Terminology	199
	Disability Independence Day in Balboa Park	200
	History with <u>Mainstream</u> and Suspension of Publication, 1984-1998	202
	Exploding Myths, Incorporated	203
	Managing Editor and Editor	207
	Justin Dart Article	210
	<u>Mainstream</u> Accomplishments	212
	Center for an Accessible Society, 1999	213
	Closing Thoughts	218

INTERVIEW HISTORY--William Stothers

William "Bill" Stothers was interviewed for the documentation project, Disability Rights and Independent Living Movement, for several reasons. First, he was a student on the Berkeley campus in the late 1960s, a wheelchair user, aware of the Cowell Residence program, but not a participant. His route to awareness of independent living is important for comparative purposes.

Later, as an editor for *The Toronto Star* (1968-78), Bill wrote a special feature on independent living in Canada in 1971, notable because 1971 was still very early in the history of this movement, predating the founding of the Berkeley Center for Independent Living.

In 1984, Bill joined his wife Cynthia Jones in her longtime work in *Mainstream Magazine*, a journal of disability news and advocacy. He assumed the responsibilities of editor in 1993. Since the suspension of publication of *Mainstream* in 1998, Bill and Cynthia have directed a five-year project, Center for Accessible Society, to promote disability in journalism.

The interviews took place at the home of the interviewer in Berkeley, California, in March, 1999, when Bill and Cindy were scheduled speakers at the Boalt School of Law conference on the ADA backlash. Bill reviewed the completed transcript and made minor corrections.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara
Interviewer

August, 2000
Regional Oral History Office
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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name William George Stothers II

Date of birth 6/24/40 Birthplace Detroit, Michigan

Father's full name William George Stothers

Occupation Hardware merchant Birthplace Petrolia, Ontario, Canada

Mother's full name Mamie Pearl Zimmerman

Occupation Nurse Birthplace Wabash, Indiana

Your spouse Cynthia Adair Jones

Occupation Publisher/Advocate Birthplace Terre Haute, Indiana

Your children 0

Where did you grow up? Detroit until age 8; then after Embro, Ontario, Canada

Present community San Diego, CA

Education High school, Woodstock, Ontario; University of Windsor, Ontario, BA Journalism; Univ. of California, Berkeley, M.A.

Occupation(s) Journalist

Areas of expertise General news; disability issues, media

Other interests or activities Photography, reading

Organizations in which you are active _____

INTERVIEW WITH WILLIAM STOTHERS

I POLIO AND EARLY CHILDHOOD IN REHABILITATION CENTERS AND
MAINSTREAM HIGH SCHOOL: THE LACK OF SOCIETAL EXPECTATIONS,
1940-1959

[Interview 1: March 10, 1999] ##¹

Birth in Detroit, Michigan, 1940

O'Hara: Let's start with where you were born and when and a little bit about your family.

Stothers: I was born in June of 1940 in Detroit, Michigan. I grew up in my early years in a suburb of Detroit called Grosse Pointe Woods. All the rich people lived in Grosse Pointe Shores. Although Grosse Pointe Woods, as I understand it, has subsequently become rather tony. We lived there at 1783 Hollywood Avenue. I remember my original address. We lived there until I was eight years old, at which time we moved to Canada. My mother was a registered nurse in Detroit. She worked at Women's Hospital. She was from Wabash, Indiana, originally. She was from a fairly large family. Her name was Mamie Pearl Zimmerman. Her mother died at a fairly young age, and her father--it was very interesting--had been in a streetcar accident, I believe, and had been institutionalized because he had incurred a head injury. He had at one point, I'm told, attacked members of the family with a large knife and was having problems. It was only in much later times that we learned about that when growing up, because my mother never talked about it.

My father was from Canada, from Petrolia. He was a first-aid man. He had worked in a number of different places in Detroit in the thirties and forties. He worked at a place

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

called Briggs Factory as a first-aid technician. For years he wanted to be an eye doctor primarily, I think. That he didn't wasn't a lifelong disappointment.

O'Hara: What did you glean in terms of values from your parents?

Stothers: That's a very interesting question. One of my strongest memories is of having played with matches. Big wooden matches. The punishment for doing that was to be forced to sit on the front porch, on the front steps, and light an entire box of matches. It got very boring very fast, and I had to do this. I think it was a question of issues of responsibility and honesty that were the primary things that I was instilled with. Another time--I must have been very young--well, I lived there for my first eight years. Sometime in that period--I think in the early to middle period--I must have taken something from a store because my parents took me to the police station, having found me out. The fear of God was put into me at the police station. Those were really primary things that I remember from that. It really was a strong issue of responsibility and honesty.

O'Hara: What about the value of education? I noticed you have a lot of it. Did that come from home?

Stothers: I think it did. Interestingly enough, when I was in probably the first grade--I don't remember too much else in the early years about this--I was sent home because they wanted to put me into--I'm not sure if it qualified as special education then--but it was some sort of remedial program they wanted to put me into because the teachers felt that I was "afflicted with a nasal twang." [laughs] Needless to say, I did not go into any special classes for that. But it's interesting about education--it is true, because both of my parents were involved with medicine in a sense, my mother as a nurse and my dad as a first aid technician. I'm told that when I was very young that I was very precocious and that I knew the names of all the bones in the body. I learned my anatomy lessons and I could recite it on command. It would be brought out at parties at our house or whatever.

O'Hara: Did they teach you that?

Stothers: My parents taught me that. It's information that did not stick forever, but it was very interesting that they did push that. And I was a voracious reader as a child. I used to go up to bed and hide under the covers with a flashlight and read books and things like that until I was caught. I don't know where the books came from when we were in Detroit. I think that they

were plentiful. I don't remember going to the library at that time. But books were very much available. Children's books. My memories of books really come later, but I know that I did do that then. I have that memory that's there.

O'Hara: Did you have siblings?

Stothers: I have a sister who's two and a half years younger than I am. Her name is Kathleen Anne. She is a terrific person. It was very interesting later on growing up with issues of disability entering our family. It brings its own problems for siblings who really feel shut out or isolated by it more than, in some cases, the person with the disability because the attention that disability commands in a family can lead other people feeling somewhat abandoned. I think to some extent that that happened. Interestingly enough, I think that like many brothers and sisters we fought a lot. Not so much in the early, early years, but in the teenage years we fought. We were not really close, but we've come to be very close in later years as adults after I graduated from college and my sister became a teacher. Now she does something totally different but she started out that way.

Family Move to Canada to Avoid Polio Epidemic

O'Hara: Was the move to Canada a big move for you personally or for the family?

Stothers: I don't remember it being a big deal. My understanding was, and it's very interesting how this happened, our neighbors in Detroit--the Macks--Ted Mack had always wanted to buy a hardware store and run a hardware store. They used to spend some time in the summertime on the Canadian side of Lake Huron in a little town called Bayfield. Ted Mack ultimately left his job in Detroit and bought a hardware store in Bayfield. We used to go and visit them on occasion, and that's where I think to a certain extent my father caught that bug about maybe owning his own business, his own hardware store, that this seemed like a great idea at the time. I think my father felt some disappointment--this is more of an intuition than anything stated--that he wasn't as advanced in his own career as a medical technician. I think he harbored this kind of idea of becoming a doctor, which he didn't have the background or wherewithal to go to medical school at that time. In part because of that, he and my mother spent some time looking

around in Canada for a similar situation that their friends had found.

I think it was also motivated at the same time, from what I later learned, that my mother especially was worried about polio as something that was epidemic in the summertimes. They thought that they could perhaps avoid it by moving to Canada and moving to a different, smaller place. The town that we moved to, where my father did buy a hardware store, was called Embro [spells]. It was originally a Scottish community; it was very Scots-focused. It was believed that the name Embro was kind of a bastardization of Edinborough, but with the accent it came down to be Embro. That's what non-Scots heard. It's a town of no more than 620 people. It still is about the same size; it's not very big at all. There's one hardware store, a barbershop, and not a great deal else. He ran that hardware store from 1948 until I guess into the late sixties. My mother had not been working full-time--raising my sister and me. But she did go back to work when we moved to Canada. She worked in what they called Ontario Hospital, which was a state institution and which housed many people who might have been classified as retarded at the time. Sadly, the only thing at all wrong with many people there was that they were kept in an institution: they had either been troublesome or whatever, and their parents had put them away in this institution, and they languished.

O'Hara: Did you have some awareness of that when you were smaller?

Stothers: Oh, definitely. After I came back from the hospital and returned home, my mother used to bring people from her hospital out to spend time at our house, to clean house and whatever. That gave them a day out, and they ate with us and had real meals. It was kind of an outing for them. They were terrific. They were really very nice people. There was no reason for them--it was one of those cases where people had been put away, thrown away--because they had perhaps crossed somebody or had behavioral problems and had no place to go when they grew to adulthood. It was very interesting. So she did that work. She worked there becoming ultimately the chief nursing supervisor, I think, of the institution, before she retired in the late seventies.

Onset of Polio and Years in Rehabilitation Hospitals, 1950-1953

O'Hara: You mentioned your own hospitalization. You had polio when you were ten?

Stothers: Right. It was 1950. We had been living in Embro for a couple of years. I went to a two-room school from grades one to four in one room and grades four to eight in another. Embro is in Oxford County, and the biggest town in the county is called Woodstock, which was about 20,000 at the time and it's where the high school was. We were eight to ten miles from there. So I was going to school in Embro and I was in the fourth grade in 1950. I "graduated" in the summer of 1950; I had finished grade four and would have been going into the big room.

I had a very active summer. I was doing a lot of bike-riding around--miles and miles. Very active generally. For some reason I picked August 18 as the time that I went to the hospital. My recollection is that it was a Monday and that on a Sunday I had felt badly. At night I wasn't sleeping, and I was just out of sorts. I went in and got in bed with my parents. In the morning, my mother at that time was home, and my father had gone to work. I jumped out of bed and fell on the floor. They called the doctor, and he did the test of bending your legs up and your knees against your chest and you feel the pain in the small of your back. That's when he suspected that it might be something, and they took me to a hospital in London, which is about twenty-five miles away. Victoria Hospital. They did a spinal tap. And I didn't come home for over two years. In Victoria Hospital I was in an isolation ward for three months--August, September, October. It was the end of November that I had nearly died in the hospital at one point. People used to come to visit, you know, on the walkway outside the window where I was.

I was pretty fully involved from polio, although I was not in an iron lung ever.

O'Hara: What do you mean when you say involved? Paralysis?

Stothers: Pretty much total paralysis. All four limbs. I'm left handed, and I could gradually walk my left hand up to my face. My left arm is actually the most efficient part of my limb now. I was there for three months. I don't have great recollections of it. I remember a lot of reading again there, the Hardy Boy books were a favorite then. We left everything there of course, because it had to be sterilized before it could leave.

Books that go through an autoclave don't turn out very well [chuckles]. So it was pretty interesting.

I lost a lot of weight; I weighed eighty-something pounds when I went into the hospital there. In three months I lost about half that; I weighed under fifty pounds. And I had no appetite. I was so sedentary. At one point my skin was very sensitive. A sheet was painful to have on my legs. I had those hoops they put in with bed clothes over it.

O'Hara: To keep the weight of the bed clothes off your feet?

Stothers: Yes, when I did regain an appetite and I wanted something, I really started craving things like hamburgers. I really wanted that because I didn't like hospital food. They kept trying to trade off on me. They wanted to fatten me up. They said if I drank these eggnogs that they made--homemade eggnogs--that they would then allow me to have a hamburger. Eggnog was not like you get from a dairy; it was with lumps in it. It was not at all attractive. It was a bargain I would not buy. I was very stubborn; I think I must have learned that along the way too. I remember the first time I was there somebody tried to move me from the bed, and they picked me up to move me--I think to put me on a stretcher to go somewhere--and it was the first time that I had been picked up that way. My knees and hips bent and I thought I was going to die. The pain was amazing. Of course after therapy started, and I started exercising my joints a little bit, that passed. I've been very free from pain since then; I don't have that joint pain very much at all. But that first time was pretty awful.

So I was there for three months. Again, I learned later--because I did not hear it at the time--that my parents later told me that doctors at Victoria Hospital said they should put me in an institution and get on with their lives.

O'Hara: What did your parents say?

Stothers: My parents laughed and said that's not an option. So then they moved me. They had me taken by ambulance to Toronto, which would have been about 120 miles, to the Hospital for Sick Children. On the way to doing that I came back to Embro and went back into my house--we were renting a house at that time--and had lunch there. I figured I was going home. I was going to con my way into staying home, which did not work. I still remember my mother used to make this stuff that I would not eat today. She would grind up baloney and sweet pickles and some Miracle Whip. That was one of my favorite things at the time.

That was my lunch. Some of the kids from school came by, so I saw people.

Thistletown Rehabilitation Center for Two Years

Stothers: Then I was taken again by ambulance, which whisked me to Toronto. I was in the Hospital for Sick Children in Toronto, which was a really old building, and I was there for about three days as they evaluated me. It was the kind of place where they had cockroach races under the bed at night. It was an old, decrepit building that was replaced within about two or three years of my having been there.

I was there for three or four days and then moved to a place called Thistletown, which was a facility maybe twenty miles outside the city. Lovely grounds. It was basically a rehabilitation center--loosely using the term--for children with all kinds of disabilities. There were people there with rheumatoid arthritis, a lot of polio, and there were smaller children with other kinds of diseases. I remember one little boy who had open sores all over his body, and also inside his mouth and things like that. He was always kind of bathed in ointments. So it was a pretty wide-ranging group. The building was in the shape of a large T. There was administration and therapy down in the leg of the T. The cross part of it was kids on one side and then at the other side were all the junior boys, senior boys, junior girls, and senior girls. I was kind of in the break point, so I was in the senior group. There were like sixteen to twenty people in the wards. We were a pretty rowdy bunch.

O'Hara: What was the purpose of this rehab facility?

Stothers: I'm not sure what it was, because when I was there that's where I first got a wheelchair. I was very skinny, and they were getting me to the point of at least sitting up in a wheelchair, which I had not done before. They were giving me whirlpool treatments and occupational therapy where I was in this big old adult-sized chair and I was very small and skinny. I could not use my arms. On both sides would be a metal rod that went up each side and then straight out. And they had like slings that were on springs--remember those?

O'Hara: To rest your arms?

Stothers: That's right. Exactly. You're bouncing around doing stuff like that and then trying to do crafts and things. One of the things I got to do was use a small loom. I made a scarf that turned out I think to be fourteen feet long [laughs]. It was about four or five inches wide [laughs], but I didn't know how to stop; nobody ever said how to stop. So I did that and some other things. Actually I made a thing out of a small piece of black velvet with some shells and things--little seahorses--then we put it in a gold shadowbox frame. I still have that. I gave it to my parents, and I have it in my house now. It's kind of neat.

"Rowdy" Patients and "Sadistic" Hospital Staff

O'Hara: When you said you were a rowdy bunch, what do you mean?

Stothers: We were limited. And I'm not sure exactly why, if it was just an issue of control or what. Like when I was in London and they didn't want to give me a hamburger unless I did something else. It was this kind of exercise of power over people. When we were in this rehab place, my parents came every two weeks to visit me. They drove a hundred miles in almost any kind of weather and no freeways. It was remarkable. But they were limited; you were supposed to only bring in to your kids oranges or ginger ale. That was it. They couldn't bring you a tuna sandwich or something you really liked. So we spent our time trying to devise ways to get out of that, to violate those rules, to get parents to violate the rules and to bring real food in. The food was not very good. It would often sit there uneaten.

The ward was a long ward, beds on either side, and a row of windows and a door to the outside on one end. They had a big table there. Well, they would put dessert there, which tended to be either canned fruit or whatever it happened to be. But that would be the most edible portion of any meal. But you had to eat everything to get that. It was put in front of you so you would have to do that. It was kind of sadistic in a way. People of course couldn't get out of bed to get to their stuff, by and large.

O'Hara: What do you mean? They couldn't get out of bed to get to their food?

Stothers: Well, they couldn't get to the dessert. You would have a tray in bed. I couldn't get out of my bed on my own, and most of

the other people were in casts and things like that. They used to do a lot of spinal surgeries to correct scoliosis on people. I have a pretty severe scoliosis, or what's diagnosed as kyphoscoliosis because it goes every which way. One of the things that they did was they did these spinal fusions and they would twist people. They would put them in a cast. Say if your spine bent to the right, curving like this [gestures], they would put your right leg in a cast, your body in a cast, and bend you kind of wishbone against the curve. It would go up and they would do like a plaster halo around your head. So you had a body cast that your head was kind of in this way--it was just an awful kind of position to put people in.

O'Hara: Did you have that?

Stothers: I did not have that. After I had gone home later, I had to come back every three months for checkups to Toronto. One of the things they did was to monitor me for changes in my spine because at that point it was straight. But they missed it in one of these periods. By the time they had caught it it was too late to do anything. Fortunately I did not have a spinal fusion. I would be less mobile today if I had had a spinal fusion.

O'Hara: In one of your columns you also referred to the sadists up there.

Stothers: I did do that in a recent column. Somebody in Toronto had seen a column I had written and wondered if I was the same Bill Stothers who had been in Thistletown, and in fact she was one of the people there. She had talked about the sadists who were there because of the treatments that they gave. It was always this kind of carrot-and-stick way of dealing with kids that went really too far. I think they did things to people that probably went beyond the bounds, that probably should not have been done. I'm not sure exactly why it happened, but there was a lot of this withholding of things, and the warmth of people was held back. It really did feel like incarceration in this place. Instead of an attitude of warmth and family and trying to get better and get to the point of moving on and improving your function, it was this kind of warehousing and incarceration and trading food for behavior and stuff like this, instead of making people feel genuinely valued.

O'Hara: How did you feel about that? Do you recall your feelings?

Stothers: No. I think I felt pretty badly, and I think a lot of that is repressed even now. I know that I was angry a lot then, and I felt abandoned by my family because they wouldn't take me home

and I didn't feel like I was getting anywhere at this place. I was in there for over twenty months, I think. They basically had no schooling. They brought a teacher in, but a teacher who wasn't really doing a great deal, and there were no demands made upon people. It was like caretaking.

O'Hara: No educational demands.

Stothers: No, not at all.

##

Stothers: One of the things that I remember was that it was a time where --this was before TV. There was a radio, and we could listen to the radio. We never saw movies here that I recall. But somehow I remember writing away to movie studios and getting packets of movie stills. You know, movie stars like Hop-Along Cassidy and others.

O'Hara: You mean photos?

Stothers: Yes. They used to send back autographed pictures of people.

O'Hara: And you did that from Thistletown?

Stothers: Yes. I used to do that.

O'Hara: At that time you could write?

Stothers: I was able to write at that point, yes. I was left-handed--I don't write very well now; my script is not very readable. But I could do it then, and it was more printing then. I also got a camera when I was there. I got a small Brownie type of camera, and I remember people would come to visit. The Toronto Maple Leafs came to visit at one time. I have all these photos; they're from down, looking up, because you had to point the camera up. It's a great perspective of these hockey stars that were coming in. It was really pretty neat.

But one of the things that happened at the time, I guess that after having been there for a while I became kind of a--I guess the word that leaps to mind is a trustee in a prison [chuckles]. It got kind of crowded. Where this T was--and the nursing station was right in the middle--right behind the nursing station were a couple of offices. One was like a doctor's office and I'm not sure what they used the other room for. They got crowded, so they decided they were going to put some people there, and they moved three of us into that area. There was room for three beds in there. And I was one of those

who got in there. The doctor in his office had a darkroom. So I learned how to develop photos when I was there. That was one of the things that I learned in the hospital there.

Also I spent time--even though I had to be lifted in and out of bed because the hospital beds were too high--I didn't understand anything about learning how to do things for yourself. Nobody ever taught me how to get dressed. I never learned any independent living skills in this hospital. I did crafts and therapy. That's about all you did. But I became friendly with some of the nursing staff. I had access to everybody's charts; I used to read charts.

O'Hara: Was this in your role of trustee?

Stothers: It must have been. I think back, and why would they let me do that? It's just amazing.

O'Hara: Were you ever asked to exercise any control over the kids?

Stothers: No. And on Sundays, a few months before I went home, at the front I even ran--for periods of time--the hospital switchboard. One of those plug-in things. It was amazing.

O'Hara: At age--

Stothers: At age twelve, yes.

O'Hara: Now when you say you were a rowdy bunch and you tried to devise ways to get around the rules, that indicates a very interesting spark of something. What was that?

Stothers: I'm not sure, because I don't think it was a deliberate attempt by staff to try to build some sort of feeling among people. I think it was a we/them kind of attitude, that we were concerned that we were average, bright kids of an age--let's say from ten to fourteen or fifteen. We were bored stiff. We were not allowed to do anything. You were not allowed to have things. You had to do what they told you to do. It was the kind of hospital where they would come in in the night and give you injections without waking you up. I hesitate to say it was malicious, because it's hard to think that anybody would be malicious, to want to just do that to kids. But the effect was the same. We all felt that we were really kind of imprisoned: we couldn't get away, we were out in the middle of nowhere, our parents could come, and if your siblings came they pretty much had to stay outside. They could look at you through the windows, but you couldn't really get outside and be with them. It was very strange. They would bring all these other people

through now and again, like the hockey players, and Elsie the Cow came once to visit us [laughter].

O'Hara: Were you pretty close to the other kids?

Stothers: I think there was bonding there, but for me at any rate it did not last outside of it. Once you were out, man, you were free and you were not looking back. Like this woman who wrote to me. I don't really remember her. She has a better memory than I do; now that might just be my own lack of memory about it. But she remembers. I have some vague memories of spending time in the senior girls' room when I was in a chair, and some of those young women were in their beds because they couldn't get out. So we would have some going back and forth--sometimes the girls were much more adept at getting contraband than boys were [laughter].

O'Hara: I was just wondering if there's any way that you, in the we/them configuration, developed any sense of power, if you ever triumphed over the system.

Stothers: I reached the stage where I was able to not be part of that system, because I was able to almost act independently. When I moved from a ward into that back room I had much more individual freedom. I was able to do more on my own and not be linked into some of the things. On the other hand I think I was taken advantage of a lot, like running the switchboard for this operation on a Sunday morning or afternoon. I spelled off other people that they didn't have to have staff do it. They may have probably had other people do that prior to and after.

O'Hara: What kind of long-term effects did this have on you?

Stothers: I think that I have been pretty anti-authority. I think that that's something that has always grated upon me, that people who set rules--sometimes irrationally, or what seems to me to be not well explained but are demanded or put in place--as attempts to just control people for the sake of control and to exercise or to establish a pecking order. I find that pretty reprehensible. I think I've felt that probably ever since then, because I can't identify it beforehand. That has always bothered me, that way of dealing with people, in any sort of thing--including the disability rights movement--when people try to use information and position to exercise power or limit others' participation and activity. I think it's wrong. It doesn't really serve the group, whatever the group happens to be. I would think that that's certainly one of the consequences of that. In many ways I've been a loner as a result of that too.

O'Hara: How did you get out? How did you know when you were finished?

Stothers: They just came. It was interesting because it would be 1952--my parents just showed up and said, "You're going home." It was out of the blue. I had been clamoring for it. My grandmother had died, and I wasn't able to go to her funeral. I was very unhappy about that. That was during that period I was there. But then they just showed up one day and said, "You're going home." My parents bundled me up and took me home.

At that point I hadn't had any real schooling during that period in there. I pretty much stabilized, in a sense, but I had no real independent living skills. I couldn't get up by myself. I couldn't dress myself. I wasn't making any more progress through therapy, as far as I could tell. Subsequent to that, what happened was that as soon as they got me home--which was ideal for me, because I was finally home after this great long period of time--my parents had started to build a house in 1950. During the time I was away, we were now living in a new house that my father basically had done a lot of the work on. He had designed it. All the bedrooms were upstairs. There were steps to get in. But my father had put in on one end of the house, on the ground floor, an addition that was going to be his den, which became my room. It had a bathroom, and he turned the closet into a roll-in shower. He took an old wooden chair with arms on it, like a big old kitchen chair, put little casters on it, and so I had a roll-in shower chair. That was my room for the next several years.

Sister Kenny Hospital, 1952

Stothers: I wasn't home very long at all before my parents decided I had not made enough recovery, or recovered enough function. So they took me to the Sister Kenny Hospital in Pontiac, Michigan, outside of Detroit. I endured the summer of 1952 in hot packs. I don't know if you went through that stage of hot packs.

O'Hara: I did.

Stothers: That was very, very hard and very uncomfortable. I don't think I gained any more function out of that either. TV was beginning to come in then, and I watched a lot of TV. I think it ruined my eyes, because that's when I got glasses. I have worn glasses ever since.

O'Hara: You watched TV during that summer?

Stothers: Yes. And most of the time, because it was hot packs, you had to be in bed for this. So I basically spent the summer in bed and getting hot-packed I guess two or three times a day. They would come around and slap this stuff on me.

O'Hara: Did they do stretching exercises also?

Stothers: They did some stretching, but it was mainly the hot packs.

O'Hara: Were you up and dressed every day at Thistle town?

Stothers: Yes.

O'Hara: But you were in bed for this one.

Stothers: Right. So I spent that summer there. Again, I was still not learning any great independent living skills at all. I came home after that eventful summer, and I really don't remember much beyond the hot packs and watching television and drinking Fago Uptown. Fago was the soda pop of the time. I guess it was just a local brand of drinks. And being able to have access to them too. Soupy Sales was a local television celebrity in Detroit at that time. Those are about my memories of that.

O'Hara: And then you went back home.

Stothers: I went back home again.

O'Hara: Were you pulled up the stairs or was there a ramp?

Stothers: I think I was pulled up the steps in the front of the house then, or in the back. Primarily the front because it was easier access.

Warm Springs, Georgia, 1952

Stothers: But I wasn't home for very long when they shipped me off to Warm Springs.

O'Hara: Really? I didn't know about Warm Springs.

Stothers: I guess that was the fall of '52. I was not happy about going. My mother took me down; we flew down. This was my first

experience on an airplane. We got stranded by rain or something in Pittsburgh. We spent a night in a hotel at the Pittsburgh airport and then finally got to Warm Springs. My mother stayed for a while. I was assured by everybody involved that this was just for rehabilitation and there would be no surgery. When I was in Thistletown I had my hands operated on for opposing thumbs. The left hand worked, the right hand didn't. But the right hand never worked anyway. It just didn't help that much. And I didn't like surgery. I was told as soon as my mother left, of course, to get surgery. I was in a body cast for five months. It was basically to loosen the tendons in my hips because all the sitting had tightened them up. This was all aimed at making me a "walkie."

They put me in a cast that was a body cast, first of all. Then every week they would split it at the hips and they would bend me backwards and put a block in. So I was bent backwards to stretch my hips. If you put me on my stomach you could rock me in this cast [laughs].

O'Hara: It sounds like torture.

Stothers: It was. When you talk about it now it sounds really bad, but you adapt to that stuff. I was in a room with another guy who was in a body cast also for another problem. His name was Jerry, and he was from Missouri, I think. Warm Springs in many ways was a really neat place. I don't know if you were there.

O'Hara: No.

Stothers: I was in the medical area because of the surgery. But they also had a theater where they got first-run movies. They had seats at the back and then this vast flat place at the front for stretchers and wheelchairs. It was like a big auditorium. I saw Singing in the Rain there when it came out. A Christmas Carol with Alastair Sim as Scrooge. That part was very, very good.

When I got out of the cast in the spring I was fitted with lightweight braces and crutches. They wanted me to walk. But walking was really never an option for me. When I got home I could stand reasonably straight but my back was going crooked and making it more difficult. I could walk around our house; I could start in the living room and go through the living room, through the kitchen and dining room and then back again. That would be about all I could do.

O'Hara: On crutches?

Stothers: On crutches, with somebody holding on to my waistband. I hated it, because I knew intuitively that this was never going to be realistic for me to do. I was not going to walk around, and I was never going to gain the strength back to make this any more than doing this. It seemed like a terrible waste of energy. I used to wear those braces to school and everything.

O'Hara: How long were you at Warm Springs?

Stothers: Only until the spring of '53. So it was like six or eight months.

O'Hara: Tell me a little bit more about Warm Springs. What about the atmosphere there as compared to Thistletown?

Stothers: A world apart. They really were. They wanted you to succeed. The whole idea of having a theater where you could have movies was aimed at reentry in the sense of living in community. If you were not in bed in a cast, you went for your meals to Georgia Hall which was set up like a dining room. There were tables for four with tablecloths. You had a menu. Granted, there were maybe like three things on the menu but you did have a choice. It was set up like a real dining room in a resort or whatever. It really gave you the sense of being part of humanity again. There was a vast difference in that sense because they respected you and they served you. They asked your opinion; you had choices. Whatever choice you made was fine. Like a resort, there was also a lounge where you could sit and read a newspaper. You had free time.

O'Hara: Did you eventually not mind being there? You said you didn't want to go.

Stothers: That's true. I wanted to get home of course, because this was now stretching on to a long period away from home, which really goes back to 1950 because I had not been home very much at all in that amount of time.

I got a new wheelchair when I was there, which I still have.

O'Hara: Was it a better one?

Stothers: It was a better one. It was not a big old clunky unfitted chair; this was an E&J chair that actually was a junior model. It had removable desk arms. It really did work for me. Although it was still very heavy, relatively. It was a good chair. I had braces and crutches, which I knew I never was

really going to use much. I was clearly able to function better when I got home.

O'Hara: You were able to?

Stothers: Yes. I was able to move around. When you have a chair that's too wide to use, you can't reach to push or whatever, I was really dependent on other people to do things for me.

O'Hara: And the body cast, braces, and crutches thing didn't do any good?

Stothers: No, because those kinds of things recur. If I had gotten through that surgery and got up and was able to walk and was going to stay on braces and crutches, that would have been a trick. It would have been done. They loosened the tendons at the hips and also on the knees to keep your legs straight. If I had been up on the crutches then and had been able to stay on crutches, it would have been really more successful. As it was, when I am really going to spend 99.9 percent of my time in a wheelchair those problems are going to recur. In fact, they recurred very rapidly thereafter.

I got to go home after that. I liked Warm Springs in that sense, but I was far from home and I was unhappy. I do remember recently that they talked about the anniversary of the death of Stalin. Stalin died when I was in Warm Springs. I had written a letter--something had happened--I had either written a letter or I had done something really goofy like send an empty envelope addressed to Stalin in the Kremlin. I have no idea why [chuckles].

O'Hara: You were always a busy little writer [laughs].

Stothers: Yes, that's right. I just did this and he died. I have no idea why I wrote this letter, but it must have been some propaganda that came out of Stalin that got me outraged.

I also got a BB gun while I was there. The Macks--the friends who had bought the hardware store--had moved to Florida by this point. They couldn't come up to visit me for some reason, but for Christmas--I was there for Christmas time--they sent me up a BB pistol. They let me keep it. It was crazy--in the hospital they let me keep it! We were able to shoot BBs out the door bouncing off the hallway walls and things like that.

O'Hara: Sounds like you did have some fun.

Stothers: Yes. I did have some fun. I was there at the same time as Lorenzo Milam and another woman who lives in San Diego named Sheila Klutzky-McCoy, neither of whom I knew at the time. Hugh Gallagher must have been there about the same time too. I was twelve going on thirteen and they were older. I spent most of my time in that medical area, so I didn't really connect with them.

Effects of Hospitalization

O'Hara: What would you say about the long-term effects on you of Warm Springs? Anything?

Stothers: I'm not sure that Warm Springs by itself was, but I think if you add the things together there is this distancing from family from the age of ten to thirteen. When I came back I went, again, back down to Detroit for another two or three months to the Rehabilitation Institute of Detroit. So there was yet another period away. But here they finally taught me how to get dressed. They did things about real life. I could get out of my wheelchair, I could slide down and get on to mats on the floor. I could roll around and I learned how to get up and get dressed. I couldn't get myself back into my wheelchair from the floor, but I was able to get out of the wheelchair. They even began to show me how to drive. They had hand controls, and they showed me that I might be able to use this and drive. Mind you, I was put behind the wheel of a car and lifted in and out. That kind of life is not really going to work for me. But they were trying to work out ways that I could transfer, get up and get dressed, and look after myself. That was the first time that that began to happen, and that was really important. The next summer I went to another place in Toronto for the summer.

O'Hara: Another rehab place?

Stothers: Another rehab place. Lyndhurst Lodge. They wanted me to do more exercise and walking. They really were pushing walking there. I was there in the summer of '55. That was almost the freest place that I had ever known, in one sense. There was a guy from Detroit who was there, and he had a problem with one of his legs--a limp. His father was a car dealer. This guy's name was Julie Fine. Julie had a big red Pontiac convertible. We could load in. We would have the staff, which was much more loose--and you could almost come and go as you like there--we would pile in his car and just go out cruising and doing stuff.

O'Hara: How did you pile in?

Stothers: There were staff there, orderlies, who would lift me in the car. People used to smuggle beer in. You'll like this, a hangover from the war. The Red Cross used to come around Wednesday, and everybody got a candy bar and a package of cigarettes. Each cigarette had a little Red Cross printed on it. Can you believe it? That's where I learned how to smoke [laughter]. I was fifteen and I learned how to smoke there. The brand name was Export cigarettes.

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O'Hara: You were just saying you went to yet another--

Stothers: Yet another place: Lyndhurst Lodge in Toronto. It was an old mansion that was converted into a rehab place. It was run by Dr. Allan Jouse. He was a physician with a disability.

O'Hara: What kind of a disability did he have?

Stothers: I'm not sure.

O'Hara: Visible?

Stothers: A visible limp. This was a place where people went to gain skills to be able to live more independently and work more independently. I went through walking stuff again, even though I protested vehemently. But it was mostly designed, I think, to build me up and give me some strength. I went through an exercise program there that was really calisthenics for people with disabilities. It was run by a guy named George, who was a double leg amputee. He was like a Marine. Just a stereotype of an old Marine. A gruff guy who insisted that people do these exercises. It was brutal.

O'Hara: Could you actually do it?

Stothers: No, but you'd try. That was the point, working at it and working at it.

O'Hara: In retrospect was that sort of a typical polio treatment or attitude toward post-polio?

Stothers: I think it must have been. I think that people didn't understand, but they thought that you must try to do the best that you could in any case, regardless of your disability, because it cut across disabilities; this was not just for polios or anybody else. There were people there with all kinds

of--either amputees or spinal cord injuries to some extent. People there were pressed to do stuff.

Mainstream Public School, 1953

O'Hara: Had you been in school at all since you were ten years old?

Stothers: As I said earlier, there was not much in Thistletown. When I went to Warm Springs it was set up that I should do correspondence courses from the Department of Education, which I kind of worked at but didn't really do much on. So when I came back--say in 1953--after I went through everywhere, I started back to school, so I had missed grade five and six. So in '53 I started back to school. I was home. This was after I came back from Warm Springs. I started in to grade seven, and I only went half days, because my father would bring me home at lunchtime, and I would get on the couch and I would listen to the radio [laughs]. I was supposed to be doing homework, but I would listen to the radio. He would set me up that I wasn't in my wheelchair but I was on the couch. And I would have soft drinks on the coffeetable and a milk bottle which I used for a urinal. Then I would have the radio if I could con him into letting me have access to the radio.

O'Hara: What was the purpose? Was this for resting?

Stothers: Just for resting. They felt I couldn't go a full day. Then the next year I started grade eight. So basically I had no grade five or grade six. Those are the times of course, in the Ontario school system, that you learn grammar. So I never had a course in English grammar [laughs]. There were four people in my grade eight class.

O'Hara: You're back in Embro?

Stothers: Yes.

O'Hara: Did the school have to make any accommodations for you?

Stothers: No. They had to carry me up five or six steps to get me into the class every day.

O'Hara: Who did that?

Stothers: I think that either my father or maybe the teacher. I don't remember that clearly. I remember being in the classroom. I can see myself in the classroom.

O'Hara: What do you see?

Stothers: I see the four of us sitting in a line. I was the only one to finish high school of the four.

O'Hara: How did you get back and forth to school?

Stothers: This was close. It was like a block from my dad's store.

O'Hara: So your father just pushed you?

Stothers: Yes, or drove me. He had an old pickup truck, and he would lift me into the truck and take me to school and take me home. I did the work in grade eight and passed grade eight. I was there all day and did the work. Then there was the question of going to high school, because there was not a high school in town. The high school was in Woodstock, which was ten miles away. The kids went by bus. My mother had to fight to get them to take me into high school because they were concerned about their ability to deal with a kid with a disability. I should have said earlier that to the best of my knowledge I was the only kid in Oxford County who got polio in that period of time. And I was certainly the only kid with a significant disability who went to that high school. I was the only one in a wheelchair that they may have ever seen. They had a lot of nervousness about letting me in, and my mother really beat them up on it. They said they would try it and see how it worked. They bought a wheelchair for me.

O'Hara: The school did?

Stothers: The school did. The schoolbus stopped right outside my father's store, so he kept my wheelchair there. They lifted me on the bus, and then the driver helped me off the bus into this wheelchair. They had a wheelchair at the school that was--"You want a wheelchair? We got a wheelchair"--big wheels in front, it wasn't wicker but it was like that, it was metal with green vinyl upholstery. It was an incredible chair. It was too big for me. I was lost in it. But that's what I used.

It was a three-story high school with a thousand kids. They arranged for me to have all my classes on the ground floor because there was no elevator in the school. When I started I had like an A average. But having all my classes on the ground floor meant that if I had five periods of English in a week,

one per day, I would have maybe two with one class and one teacher, and maybe one with another class and a teacher, and two with somebody else. They were never at the same place. All the classes were that way.

I passed the ninth grade. I passed the tenth grade, but not quite so well. By the eleventh grade I was failing because it was crazy. When you hit things like Latin--which I couldn't handle, because I just couldn't grasp it with those kinds of changes going on with teachers and classes--

O'Hara: You had several Latin teachers in a given week?

Stothers: Yes [laughs]. And they were never doing the same thing at the same place. Algebra. It was not a strong suit for me anyway, but it was really a problem and I was sinking. But I passed the year. The next year in the twelfth grade they started carrying me around. I stayed with one class.

O'Hara: Up to the second and third floors?

Stothers: They just picked it up and did it.

O'Hara: The kids?

Stothers: Yes. I was with one class. You have to remember also that in Ontario they have grade thirteen. So I was there for grade thirteen. In twelve and thirteen I did all right. But I was hurt in English by the lack of grammatical skills. I was hurt in math and sciences for the lack of real inclination and also the jumbled scheduling of trying to learn that stuff. Tables were too high to do experiments in chemistry. Dissection--I could barely see the top of the table let alone cut up a frog. Those were problems then. But I just got through.

Low Expectations and Parental Influences

O'Hara: Were you feeling that this was like an injustice to you, or were you thinking that it was just your misfortune?

Stothers: To a large extent I thought it was my misfortune, that this was all I could expect. I was glad nobody singled me out to ask me tough questions in classes. I really felt, as the person with a significant disability, so outside. I was ashamed of my own disability, of my body. I was skinny, small, my back was bad by that point. I couldn't keep up. I was using this clunky

wheelchair. I couldn't do anything, I made no friends because when school's out the bus leaves. So it was very hard. But when I look back on it the real tragedy was--and what makes me angry--is not all of that; the worst part is the low expectations they had of me. If they had really thought and really pressed me, I think that I would have had better work habits. I probably would have had better skills at doing a lot of the things that I've done since then. I think that I got shortchanged in that sense. And I think my mother probably saw that. My mother was farsighted enough to see that I wasn't going to die and I wasn't going to go live in an institution, and that I was going to grow up, and then what was going to happen to me? She knew that I had to have an education and skills and was determined that that was going to happen. I'm convinced that that progression of going to all these places--

O'Hara: The rehab centers.

Stothers: Yes, the rehab centers--it was primarily my mother's determination that I needed to get skills to do things, that I was going to have a life, that she wasn't going to take care of me for the rest of her life and mine, and that I had to have a foundation to work from, and I had to be able to live as independently as possible. I think that that really drove her. I think that she was not always supported by my father in that; I think that to a certain extent my father--this is kind of an aside from the education stuff--was deflated by my disability in some ways. I'm not saying he was disappointed in me, but there was kind of a disappointment in his life somehow that really made it hard for him--that didn't cause that to happen to his life but might have been another in a series of things in his own life that tended to kind of look more at closing off things or putting boundaries on things instead of opening and pushing more.

O'Hara: He helped you a lot though.

Stothers: Absolutely. I'm very much like him in many ways, too. I think my parents' marriage probably should have been maybe over before I got polio. But they were married for fifty-three years before my mother died. It was hard for both of them, I think. I think that maybe even my getting polio may have compelled them to stay together more. I'm not saying that was the only thing. I think that at that time there was less dissolution of families, and I think it was never really an option that they thought of, but maybe should have.

High School Valedictorian and Alcoholism

Stothers: As I say, getting back to the education part, I really do feel that in some ways I think the school was amazed at what I did. I was elected valedictorian of my graduating class. There were two groups of grade thirteen--when they graduate there are usually two or three classes--maybe sixty or seventy people out of the school graduate. It's not chosen by merit or grade point or participation; it's by election. The graduating students all get into a room and they nominate people and elect someone. I hated it.

O'Hara: Being valedictorian?

Stothers: Yes. I was nominated and was elected almost hands down. It was just totally wrong and I hated it.

O'Hara: Why was it wrong?

Stothers: It was wrong because in my view it was a pity thing, or kind of a pity/inspirational kind of thing. I hadn't been a real participant in school events. I hadn't been athletic. I was by far not the brightest person in the class; there were some exceptionally bright people who were very active. Plus the fact that I had to give a short valedictory speech. I was terrified.

O'Hara: How did you do?

Stothers: Not very well. I spoke for a few minutes. An English teacher helped me to prepare something that was perfunctory, and I gave it. There were two things that were very significant: I was given money. I think I got like \$500. Not for any scholarships or anything, but they were called scholarships because I went to college. It's an odd thing the way it happens, by the way, that the graduation commencement was in October or November. In grade thirteen there were province-wide exams, so everybody writes the same exams. They're all sent in June, and then they're sent to Toronto and marked blind. Then the results go back out, so you don't usually find out until August whether or not you passed [laughs]. This is just for grade thirteen.

Grade thirteen was instituted early in the century almost like a transition between high school and college, so you could pass grade thirteen and go get a B.A. in three years. The way they tried to use that as a standard was to have these standardized exams across the province so everybody would be

held to the same standard of work even though there would be--you'd have to read, say, three novels in English and there would be a question on each one of them, and you answer the one on the book you studied.

So I was away at college when this happened, and we had to come back for it. I was absolutely terrified about this speech. The significant things were the money that I got--I just felt really badly by the whole process. I felt it was like pity, and that was the worst part of it. The other part of it was that because I was so nervous about going to do that my father gave me a shot of whisky before I went. Well, that was by far not the last shot of whisky in my life. In fact I had a serious drinking problem for twenty years. I didn't stop drinking until 1979. When I drank it was always to excess. I loved to drink it. But I blacked out a lot; I never remembered.

O'Hara: It started with a shot of whisky?

Stothers: That shot of whisky was the first one. So that has a significant place in my life.

But I did graduate from high school, and I did very well in history and pretty well in English. I aced the chemistry exam, don't ask me how, but I aced it.

O'Hara: There was at least one other thing in your high school years. I think I read about it in one of your columns. One was a camp at age fifteen.

Stothers: Oh, yes. In the summertime I went to Woodeden, which was a crippled kids' camp near London that was a range of kids with disabilities: little kids to fifteen- or sixteen-year-olds.

O'Hara: Why did you go there?

Stothers: Because my parents wanted me to be out of the house because they didn't want me sitting around all summer just moping, because our house was not very accessible, and living in the town I was in I couldn't really just go out and roll around. I couldn't roll anywhere anyway. There basically weren't any sidewalks in our neighborhood. So this was a thing that they thought would be good for me to do, and it would be getting me outside and doing some things.

I went two or three times, I think. I didn't much like it at all.

O'Hara: Different summers?

Stothers: Yes. I didn't much like it because I felt out of place. I felt snobbery intellectually, that I was beyond most of the kids there. Most of the kids were fairly significantly disabled and I think were either in special schools or no schools or institutions. By this time I was going to high school, I had a different kind of world view than people there. I had more in common with the counselors and staff than I did with the campers. So I felt kind of caught in the middle. Again, I did my first editing job there: I was the editor of the camp newspaper, which was a one-issue thing that everybody took home with them. It had pictures in it. My sister was a counselor--not when I was there; there were junior and senior camps, and she was one of the other ones that are for the girls. They had boys' camp and girls' camp. Actually a friend of Kathy's, whom she met at this camp as a counselor, later became one of the first great loves of my life.

I'm not a camper. I had to be lugged into this campsite like over somebody's shoulder. I don't like that kind of stuff. I don't like to be in that situation. I'm just too urbanized for that stuff [laughs].

Lack of Affinity for Other People with Disabilities

O'Hara: You did mention in your town there was one kid that you kind of hung around with. As far as other associations with people with disabilities, that just didn't happen?

Stothers: It happened at the camps, in a sense, because you're forced into it. There were cabins, so you were thrown into association with those kinds of kids. The problem with that is I felt towards them as I imagine other people who are non-disabled felt around me, in the sense that I didn't like to be associated with them, I didn't want to be like them. I think at the time I probably rationalized it in the sense that because of the way they behaved or whatever, I didn't like that. But I think it really had to do with disability, about being kids who had Duchesne's muscular dystrophy and other kids who had either intellectual disabilities--that I felt superior to them--and I didn't really want to be lumped in with them. I'm sure there was a lot of that. This other kid that I did pal around with was somebody who was a regular guy who just happened to get hit by a bus and had a banged up leg. He got the mumps, and he spent his time in the lodge. I was allowed

to spend time with him because we got along, and he needed somebody to be with him because everybody else was out doing stuff. So we had a great old time.

O'Hara: In that same column you said that in the course of your life you had a humbling learning about feeling better than and different from other people with disabilities, like you said. Why? What was the humbling?

Stothers: When I look back and I see how I felt about those kids, that's the way I felt about being elected valedictorian. It's like the idea about the shame that I am like them, and that I didn't want to be like those kids, and I didn't want to associate with them. I didn't want anybody to associate me with them. I was trying to be non-disabled. Yet every time I turned around, whether it be high school where I was valedictorian, it's like I've been found out that I am different and I am not one of you. However much I want to be, I'm not. It took me a long time to begin to live with that, to begin to say that this is okay, that I am okay, and they're okay, and I can do this. If I'm okay, then they have to be okay by definition. We can't have it both ways.

When I went back to Toronto after graduating from Cal [University of California at Berkeley], I fell in with this ALPHA group, and there were significantly disabled people in that group who were terrific people. They hadn't gone to school, they didn't have the education, they didn't have the tools, and I came within a whisker of being in that same position. To some extent I was that way because the system didn't expect enough from me. These guys in Toronto were the same way: the system didn't expect anything from them, and therefore they had all this raw talent and potential and found it very difficult to manifest and be accepted in the broader community because it's not clothed in the forms that we learn in school and in other social ways. That really came home to me, but I think--and I'm convinced of this--I was only able to learn that because I had been here in Berkeley for two years.

When I came to Berkeley--we're jumping around now--I was twenty-six years old going on sixty. When I left I was twenty-eight going on twenty-four. It really changed my life. It had nothing to do with disability. It had to do with just the atmosphere of what was going on here; it was a liberating time.

O'Hara: I want to ask you some details about that and also some more about the ALPHA.

II COLLEGE YEARS, EDITOR FOR THE TORONTO STAR, AWAKENING TO THE INDEPENDENT LIVING MOVEMENT, AND A NEW OPENNESS TO PEOPLE WITH DISABILITIES, 1959-1972

[Interview 2: March 11, 1999] ##

University of Western Ontario Student, 1959

O'Hara: Just one more question about high school: were you surprised that you did so well after skipping a couple of grades because of your polio and having all kinds of difficulties in the earlier years?

Stothers: I think I was. When I think back on it particularly, there's good and bad. But the fact that when I was with one class, as I was in the last two years, it began to mean a lot more. You're with the same people, you felt more comfortable, you were on the same page all the time with the rest of the class. The things that I did better at were things like history and literature--more on the social side--rather than the hard side of mathematics or science, which I never was really very good at, although surprisingly enough--as an aside--I happen to be a very good photographer, and I notice things and have a very good spatial sense. But I did not do well in geometry [laughs]. But I knew that I could do that stuff when I was there, and I felt very comfortable doing it. That was not a surprise to me that I could manage that. When I got to college, of course, it was another matter because you go back to the bottom of the barrel as a freshman. You start at the bottom rung again.

O'Hara: How did you choose the University of Western Ontario?

Stothers: The truth of the matter is that I didn't want to go to college. I wanted to be a radio disc jockey. All through my life I had been told that I had a great voice. I thought it would be great to be a disc jockey. Radio is not visual, for one thing.

Television didn't even really enter my mind at that point. I'd be on the radio and be a disembodied voice. When you have this kind of self-image--or this body image--that I did not embrace at that time, and I rejected myself in that sense, so I thought this sounded like a cool job. My parents were very good about it. They said, "That's fine if that's what you want to do. But you really should have something to fall back on. You should go to college and get a degree." I was persuaded by that argument.

I chose the University of Western Ontario because it was close to home, I could live in a residence there, my father owned a hardware store and every Wednesday he closed in the afternoon and he went to London to buy his supplies. He brought home a lot of stuff or it was delivered. So he would be able to come by and see me every week and give me my five dollars per week allowance. And he picked up my laundry. My mother did my laundry at home, so every week I had to exchange a duffel bag.

O'Hara: Two sets of everything.

Stothers: Two sets of everything. So that's the way it went. That's really the reason we selected the University of Western Ontario.

I think I mentioned yesterday that I attended Huron College, which is a college at UWO. It's a residential college. It was an Anglican theological college where they trained priests. It was the oldest part of the university. In fact, about three or four years before I came on campus it had opened up to admit arts students because the arts students brought in more money and there was greater diversity, a more interesting kind of mix of people. It was all run by priests, although the faculty was mixed. The principal and the officers of the college were all Anglican priests. It was a small residential college, and we made a deal with the dean of residents because this was very new to me as well as to them, and I was going to need assistance and who knows what, because it was unknown territory. So that's where I lived. Right across the hall from the dean of residents and his wife. They had a child with a heart defect, so they had an empathy about disability even though at that time all of this disability stuff was very inchoate in people. People had this sense of something, but not really formulated as an idea as we do now. We got along very well; they were terrific people. Hugh B. Rooney was his name. They were very, very terrific and supportive of me. I lived right around like the first room past their apartment, so they were always available.

O'Hara: They were your assistants then?

Stothers: No. They were not. My roommate, who was a sophomore, was a guy named Michael Vaughan. He was from Toronto. His father was an executive of an advertising agency. Actually his family, Michael's mother and father, had had a child with Down's syndrome, although in 1959-60 they did not refer to children with Down's syndrome as anything other than mongoloids. I think that's the first time I had ever encountered anything like that. So there was this whole disability thing going on, but it was never really spoken of very much. Michael was my roommate for the first year. It worked really very well, I think. There were no problems.

O'Hara: He worked as your assistant?

Stothers: He assisted me where I needed to go in the morning, or somebody else would. I was right across from the dean's apartment, and down the hall was the bathroom. So I was close to everything. Now I can get up and dressed in the morning, but if I ever needed anything Michael was there to assist. It worked out. And he was also a person who had a lot of friends from Toronto or wherever, and I got to know people that way too, because I was very shy and not outgoing at all. So that worked very well.

At the end of the hallway was another guy in a wheelchair who was in the business school. His name was David Smith. He lived with his younger brother, who was also in the business school. I think his disability was somewhat more severe than mine. He was polio also. His brother was his attendant. So that worked out pretty well. He ultimately went to law school as well, at Western.

So there was a pretty good support system there. I was very aware and angry, I think--kind of blaming myself more than anything--through this period because while I was there I went to Rush week for fraternities. I was never invited to join a fraternity. I was invited to one party, but never again. I really felt a disappointment in that, and I felt that the disability was a real factor in that although I have no hard evidence of that. I really believed deeply at the time and it reinforced a lot of negative feelings. They didn't last forever because I never knew that kind of stuff. I certainly couldn't afford that kind of lifestyle. I built friends in the residence that I lived in. I lived in a single room after that first year on my own. I had a pretty good time in that sense. I needed assistants to do bathroom businesses and to get across campus.

I had to go across a wide field to get to the main campus of the university, and I was studying journalism because that was the closest thing I could find to being a disc jockey. The most related thing. That's why I took journalism. Although I had done some of these other little things before like the newsletter that I had edited at Woodeden.

O'Hara: How did you get across this wide field?

Stothers: People would push me. Again it was just arranging somebody who would be able to take me over to class and pick me up and bring me back. The journalism department was on the second floor in the gymnasium building, and it was a walk up; there were no elevators. So you had to go up like six steps into the building. The campus was all built in a limestone kind of Gothic and old English style building. There's a step to get in the building, and then there were like six steps up to the first floor. Then you had to take a stairway up to the second floor. People had to carry me up. Journalism professors would come down and help carry me. Everybody. It mostly always worked.

O'Hara: And that went on for four years?

Stothers: Yes. In the wintertime [chuckles] they would take me over on a toboggan. They would fold up my chair and pull me on a toboggan and somebody would push the chair. Unfortunately I never really got this worked out: I'd be sitting facing the front of the toboggan, facing the way I was going, and try to sit up because I have very poor back stability.

O'Hara: They didn't put the chair on the toboggan.

Stothers: No. And my legs are straight out in front of me as best they could be straight, and snow of course is coming up my pant legs [laughter]. So there were times that I would skip some of those classes. I'd say, "I think I'm going to pass on this one." I did not have to go over there for all classes because a lot of the core classes that I took--I took English and economics and philosophy like I took at Huron College--so I didn't have to go outside, period. That was really very good. They had an elevator at Huron College in the library that I was able to go up and down and get from floor to floor to the dining hall, so it worked very well. It wasn't designed to be purely accessible, but for the most part it was pretty good.

O'Hara: You chose journalism because it was the closest thing to being a disc jockey?

Stothers: What I really wanted to do was be a disc jockey.

O'Hara: I noticed that you graduated with honors. What was that all about? What gave you the honor?

Stothers: That perhaps sounds better than the reality. The reality is--remember if you go to grade thirteen--you can go to university and get a general B.A. in three years. But most courses, like journalism or engineering or other professional courses like that, were four-year courses and they called those honors programs because it was an extra year. They gave you the honor of being there another year. That's what it amounted to.

I did not set the world on fire, but neither did I languish too much. The journalism part of it was pretty good, but I think it's much improved now. I think they do a much better job now of teaching journalism and teaching more things about journalism. It was a nuts and bolts kind of thing when I was there. You really learn more being on the job and working on the campus newspaper and taking economics and political science. You would be better off doing that than taking journalism. I would advise that now to young people that I see, because I think you need specialized knowledge and deep knowledge of other fields. And you can learn journalism and learn how to write if you have an inclination to that; you can go into journalism and be taught, in many places, on the job. They also helped me get my first job, so I'm certainly not knocking them.

Job with Globe and Mail

O'Hara: That was in 1963? Did you go away from college?

Stothers: Actually 1962. It was a summer job. It was my first real job. I interviewed for a summer job. They had come to campus. I was being very cheeky at the time, saying I was going to go in and have this interview and then I was going to turn around and leave with a sign on my back that said "Hire the handicapped." But I did not do that [chuckles]. I waited and waited. The interviews were in the late winter, I guess, in maybe March. School went through the end of May. I waited and waited and never heard anything. I had an interview with the Globe and Mail, which is a newspaper that calls itself "Canada's national newspaper" and is very much like the New York Times, or likes to think of itself in that way. I didn't hear, so finally I called and asked if any decisions had been made. Either they

hadn't made decisions or didn't know what to do or whatever, but anyway three days later I got a job offer. There were actually two or three of us from the department who were hired on for the summer. So I began my career there in the summertime, and then at the end of the summer they asked me to rejoin the paper full time when I graduated the following year.

O'Hara: And you sailed right into that.

Stothers: Yes.

O'Hara: When you started full time, what was your job?

Stothers: In the summertime I was on the rewrite desk. The Globe and Mail produced several editions, and every edition changed. So they took a lot of new information and they covered a lot, depending where the editions went. Like in Ontario, outside Toronto, one would go south, one would go north, one would go west, and one would go east, and there was a metro edition. So there was a series of stringers all over the province. These people all would call in with information that would be packaged in some fashion for that area. That was a lot of it. Plus there were national correspondents in Ottawa or on the road, and they would call in on deadline when they were traveling with politicians or whatever.

When you're a new boy on the job, as I was, what we were doing was taking dictation and of course a lot of these stringers would send stuff in that needed to be rewritten, but what did I know? I would just take dictation and turn it in. I was afraid to do anything. This was right at first. But the first night on the job I could not use a regular desk or a manual typewriter. So they had purchased, for my use, a small Smith-Corona electric typewriter. They put together two file cabinets that you could build a desk out of. You could take the two grey metal file cabinets and pull them apart, and they had this thing that fit in on top in between the two. There were two slots and this top would drop in. That was the perfect height for me; it was great.

So here I am on the headphones, and I'm typing away, and I was taking dictation from a guy who was one of the primo prima donna reporters for the paper and who was in British Columbia filing on deadline for the first edition of the newspaper. This was like seven-thirty or quarter to eight on my first night. I'm typing away and taking this stuff down and I'm terrified of making mistakes, and I'm going as fast as I can. I notice that the typewriter--because of the motor there were vibrations--was gradually moving, and the two file cabinets

were moving apart. Finally [laughs] it fell apart. Here I am down here like this [demonstrates], bent over still trying to type with it, and this headphone thing was on and pulling--what a mess! People were running and trying to get it done, and this guy was trying to file a deadline story, and I was panicking. I thought, "I'm out of here, I'm finished. I'll never work again." But it was just one of those things, and they carried on. Boy, that was really a baptism of fire.

But I have to say that they worked me hard. I talked to you yesterday about the low expectations or the lack of expectations in high school. This was the real world. They would cut you a little slack for a little while, but it was either perform or die. I was very appreciative of that. I didn't like it in some ways at the time because when things get thrown back at you, and you haven't had that experience before it was a very hard learning experience for me. But it was a good learning experience. Then when something truly was acceptable, and you make those kinds of improvements in what you do, it helps a lot. It's certainly great for your confidence. That meant a great deal to me. That summer was very good.

O'Hara: Why did you prefer an electric typewriter? Was that more useful to you?

Stothers: I couldn't type on a manual. I don't have enough strength in my right hand to hit the keys.

O'Hara: So the advent of the electric typewriter made a big difference.

Stothers: That's right. You may or may not be aware of this, but IBM--even then, back in the fifties and sixties--would sell people turned-in old electric typewriters. I had this old monster that must have weighed fifty pounds. It was a big old black typewriter, looked more like an old typewriter than a new Selectric. I never got a Selectric. It kind of sounded like a coffeepot. But it was great. I got through college typing papers on that typewriter. It was a marvel. And IBM even then was making its technology available to people with disabilities.

O'Hara: So you started there fulltime. Could you summarize your various positions at the Globe and Mail?

Stothers: I can do that. I started on the rewrite desk after college, which is where I had spent the summer. I spent almost a year on the rewrite desk, which is--on the east coast, particularly on morning newspapers--it tends to be a very crucial part of

the operation because a lot of information comes from a lot of different places and is put together there right at the rewrite desk. You would take things from wires, from correspondents and whatever and produce copy that goes into the newspaper. Or somebody would give you three or four different elements that they wanted put together. When you're working on typewriters or cutting and pasting, which a lot of it was because everything was done by hand in those days, the rewrite desk was very important. There were four people on the rewrite desk, including myself, on any given night. That's where I started. It was hard work, but it was rewarding work. I was passable. I wouldn't say I was great at it. I wasn't a born rewrite man. My mentor there, with whom I ultimately moved in with and lived with for some time, was a born rewrite man. He retired just a while ago from the rewrite desk. That's where he spent his career. He was terrific.

I went from there into a weekend section. In Canada at that time there were no Sunday papers because of the Lord's Day Act in Ontario and in other parts of the country. Nothing happened on Sundays. The country pretty much closed down on Sundays. Those were the old days. Newspapers didn't publish then either. The Sunday papers were the Saturday papers: that's when you got the color comics and you got the weeks in review and all that stuff. My job was to do a week in review column for the Saturday paper, which was something like USA Today now runs every day where there's a little blurb from each state. Something happens that's newsworthy, and that's what they did.

I would go through on a weekly basis--I had to take the rolls of copy from all over the country that came through our office from the wire services and look for interesting things and put together a column like that--but that was only a third of a page. But I had to try to get something of interest from all ten provinces. So I spent a lot of time doing that and doing some other editing. There was a three-page section that we worked on, and this gets to a person I mentioned before but it may not have been on the tape, and that was Frederick Nossal. There was a Canadian page, an across-the-country page that I did, and then the front page was kind of a world page that looked at world events. Frederick was the editor of that page, and he also wrote a signed commentary on the page every week. So we worked very closely together.

Fred was an Australian newspaper man, and he was now back in Toronto. Prior to that he was the newspaper's correspondent in China. He was the first North American newspaper correspondent to be resident in China after the Communist

Chinese regime came into power. This was in the late 1950s, and so he was there from like '58 or '59 into the early sixties, and then he came back. So we spent a lot of time together and became quite close friends. That's what prompted in me a great interest in things Asian, particularly Chinese. It was just fascinating stuff.

I did that job for about another two and a half years. I spent a year from '63 to '64 on the rewrite desk, and '64 through '65 on this other project. I had planned for a long time that I would like to go to Europe and do some traveling, and I knew that the Reuters News Agency in London hired people from North America as editors. The cycle they worked was six days on and four days off, and I thought that I'd be able to travel anywhere in Europe for periods of time and see a lot and spend a couple years doing that. Well, until I learned when I had a bad cold that my doctors told me to quit smoking--which I had been doing for ten years--and if I went to Europe I could do that, but I probably would not live more than about a year because of the impact of damp, cold, weather on my lung capacity. Not exactly having a death wish at that time I decided I wouldn't do that, but I felt that I needed to make a change in my life.

So I decided that I would go back to school and study history because I had a long interest in history, and I thought I would do a make-up year in history at the University of Toronto to get enough credits to go into a graduate program of history at the U of T. In fact, that's what I did. One sidelight: when I left the paper--I heard this later from one of my friends at the paper--that my supervisor, who was not Fred Nossal but another person who was an editor who was originally from Scotland--was kind of perplexed. After I left he said, "I really can't understand why Stothers left the newspaper. Whatever else could he hope to do?" Basically I had been perceived as being in a place and pigeonholed in a spot where I had no future advancement.

O'Hara: That's how he saw it.

Stothers: That's how he saw it. I thought, "I am well to be out of there." But it was very interesting because I had no inkling at that point that anyone thought that way. On the other hand, when I look back at it realistically too, and I see the kind of way that I looked at myself, that my expectations of myself were so low that in some ways it might have been self-fulfilling. I might have thought, "Well, I'm here. I've got a job, and I can do this, and I'm struggling with all these disability-related issues about just having to try to find a

place to live on my own and get transportation to and from work. Those are hassles to be added on to the day." In some ways I can see that I might not have been really exuding the kind of aura or impression of wanting really to be the editor of the newspaper, of really having my eyes on advancement and doing other things. It was more of a "protect what you have" attitude. In a way, it's probably a good idea that I left.

O'Hara: You did take one year to study.

Stothers: I took one year to study. I stayed at New College in Toronto.

UC Berkeley Student, 1966 ##

O'Hara: You named the courses that you took.

Stothers: Plus I took one in modern Asian history, which was kind of a survey course of East Asia.

O'Hara: You finished that in the summer, the Chinese language?

Stothers: I did all of that, and then I took the Chinese course because of my relationship with Fred Nossal and I really became very interested in it. I had a professor who was a specialist in Japanese intellectual history. His name was Thomas Havens. He was a graduate of the history department at Berkeley. I was going to stay at the University of Toronto and do further graduate work in Asian history, particularly with Havens, but at the end of the term he decided that he didn't think really that there was much commitment to Asian studies at the University of Toronto at that time, so he took a position at Connecticut College. So I was left somewhat high and dry.

He knew that and was keenly aware that I was in a state of high disappointment. So he made some calls to his friends in Berkeley in the history department and arranged for me to make an application and to be accepted into the graduate history program starting in the fall of 1966. I proceeded to prepare to do that, and also he found out about and urged me to apply to go to Middlebury College in Vermont to do an immersion course in Mandarin Chinese, which was ten weeks. I did that and had a great time.

I learned to speak rudimentary Mandarin and to read it. I'm very visual, in a sense. Though I was not very good at geometry, I was very good at the Chinese written language. I

loved it. I still have Chinese dictionaries that I look at now and again. I met a lot of people at Vermont who later came also to Berkeley to study in the history department.

I had a little bit of time off before flying from Toronto to San Francisco. I didn't really know where Berkeley was except that it was in the Bay Area, and I thought you had to fly to San Francisco. I flew to San Francisco in late August or early September of 1966. This was a time when the University of California at Berkeley made the switch from the semester system to the quarter system. That began that fall, and I arrived in San Francisco late at night. I had had a few drinks on the airplane coming out, so I was a little bit spacy. I didn't have the slightest idea how to get to Berkeley, and I was traveling alone with all my luggage.

I got there. I guess somebody put me on a bus, and I wound up in Berkeley.

O'Hara: Did you have a place to stay?

Stothers: Yes, I was to stay at the International House. This was late at night then. Of course there were lots of steps to get into the International House. Finally somebody tracked down a way to open the gate where they make deliveries. It was a wire mesh gate, we had to undo the padlock and let me in, and I came around to the front and got registered and found out where my room was and all that. I went upstairs in the freight elevator. The freight elevator was my mode of transportation in I-House [International House]. I got to my room and managed to get unpacked and get the room arranged in such a way that I could get into bed and get up in the morning. That much I could do. Thus it began, my career at Berkeley.

O'Hara: And when you visited this week did you go in the same entrance?

Stothers: I did not. I came back this week and they now have a ramp. I understand they did have a lift of some sort at the front until just recently, but now they have a switchback ramp that is very good. It's very easy to go up and come in the front door, which is very refreshing.

O'Hara: Do they have automatic doors?

Stothers: They have automatic doors.

O'Hara: A little bit different.

Stothers: Yes. I had forgotten a little bit, but the ground floor is tile, and they're like a cobblestone effect. Using a wheelchair is very bouncy on that. I remember when I came here thirty years ago I was in a manual chair. That was very bouncy to ride on, although it didn't have carpet, which was good, because carpet is very difficult in a push chair.

O'Hara: Can you describe the campus at that time, in 1966? What are your impressions?

Stothers: I lived at I-House, which is at the top of the hill, and I had to go down Bancroft every day. My way of getting there was to go straight down Bancroft and in through Sproul Plaza. I could go around to the library, and the history department was to the left. I don't know if it's still there or not; I didn't get on campus very much yet to see if it's still in the same place.

O'Hara: Was it in Dwinelle Hall?

Stothers: I think so, yes. Most of my classes were there. My first professor, whose name I can't remember--I do remember the fact that he was from New England, I think--had the image of an older statesman: white hair, specialist in early Chinese history. His father had been a U.S. senator. He was a wonderful man. He presented this course, and he was not in Dwinelle Hall. He was near retirement, I think, so he was placed somewhere in older quarters. He lived near campus. The quarter system started and he basically said, "I've been doing this for decades on the semester system. You're just going to have to learn the same amount of material in this time."
[laughs]

O'Hara: No rethinking.

Stothers: I thought, "This is not going to be happy." But it was still a very interesting time because he was passionate about it, and it was interesting material.

The other thing I remember is that he invited his graduate students to his house at Christmastime, which is something I had never experienced before. Having people over to your house for a dinner party for your students, I thought that was a wonderful thing to do.

Personal Identity and Political Aspects of Berkeley

O'Hara: You said yesterday that your experience at Berkeley was very liberating. Why?

Stothers: I was an old twenty-six when I came here. I tended to be--and I'm not sure exactly why it was--kind of conservative in my lifestyle and traditionalist in my thinking. Music-wise I tended not to like modern rock and roll or Elvis Presley or any of that kind of music. I listened to classical music. I tended to read more intellectually, traditional materials: newspapers and magazines and the like. I was kind of stodgy.

Partly I think it was that I was reserved, and I think this has a great deal to do with disability: you're never sure how people are going to react to you, so you kind of hang back and wait until you respond to people reacting to you rather than initiating any sort of behavior. The idea of going into a room and taking the initiative and glad-handing people is something that I never would have done. I think that was a learned behavior over time, and so I tended to be very much reluctant or reticent in the way I was in groups and reacted to people.

Plus having a sense of personal inferiority and questioning whether I ought to be here or not. Coming to Berkeley, where I was in a graduate program where people had come to Berkeley from, say, four years of undergraduate work with a major in Chinese history from Harvard or Yale or wherever. It was just amazing that here I was with this one survey course of modern Asian history [chuckles] and not knowing what these people were talking about. It was very high-powered, and I must say I was intimidated by all of this.

So that's where I was when I came here. Some of that never left. I realized very quickly that the idea of pursuing a Ph.D. was not for me. I certainly just didn't have the makeup to push myself to that level. But living in International House and dealing with people here and being exposed to popular culture, as everybody was here then--I mean, Telegraph Avenue at that point was a very creative, flourishing place. People were very open and inclusive. I felt much more comfortable among people. I think there were less stereotypes, I guess. People just took you for who you were and included you. This was a very creative period here socially. And politically of course, it was just explosive. It was very exciting, and you couldn't hardly avoid participating and being involved in it. And I got involved.

I had friends here--several from Canada--and they were all in graduate school here, and I had met them at International House. There were two or three people from Canada whom I had not known before. They moved into I-House but decided that I-House really wasn't for them; it was a little bit too restrictive, so they moved out. Before that happened, they had still made commitments to be at I-House and some were taking their meals there. Not everybody moved out at once out of that little group, but some were there and some weren't. So we kept a case of scotch in my closet and we had happy hour every night before dinner. We had a small group of people that included people who stayed in I-House and some who left. Mostly these were people who were very interested and were younger than I was, but who really embraced what was going on.

O'Hara: What was going on?

Stothers: It was the rock and roll culture, it was the drug culture--although I never saw any evidence of drugs. I saw people smoking marijuana. I never took or smoked drugs in Berkeley. I guess I didn't need to [laughs]. Scotch was my drug of choice. Even then you'd be very careful about what you ingested anywhere. These were the days of LSD and other kinds of drugs, and you just never knew what would happen to you. But some of these other people were much more eager to embrace that kind of stuff. Just by nature I'm a little more cautious about that.

Being with them, they didn't subject me to any of that, but just the music and openness and debates. When I was at the University of Western Ontario people would sit around one of the big common rooms--people there played bridge and cribbage all the time. It was a very exciting time just to be here talking to people.

O'Hara: What was the political aspect of the times?

Stothers: The politics of the antiwar movement were going on.

O'Hara: What did you see?

Stothers: There were demonstrations on the campus, there were confrontations and sit-ins and people occupying the plaza. This was after the Free Speech Movement, which had been '64, I guess. It was a very highly charged atmosphere all the time. People were willing at the drop of a hat to do anything. The military recruiting on campus was one of the big issues of the time. As a Canadian I was very interested in all this although it didn't affect me directly, and certainly not the draft or

any of that. But the intensity and passion with which segments of the student community engaged in this stuff was really exciting. I had never been around anything like this; the liveliness of it all was really very intoxicating.

As you know, the International House is right beside the stadium. Then football season would be going on and all these people would be trekking up to the football games. There were these separate worlds. You had all the fraternity houses up around that area. A lot of people who were part of the student body could care less about this political stuff. They were there as traditional college people having a college-good time and studying and doing whatever. So you really had a dichotomy there. Plus in International House you had a lot of graduate students from all over the world who were very interesting in and of themselves, and were often trying to figure out what these people were doing here [chuckles]. All that was very, very stimulating for me.

I was very ambivalent in some respects because all that stuff was very intoxicating in the sense of being engaging and to see it happening and to be part of it. Being exposed to that stuff I became much more interested in it, and getting into the music of the time particularly is a thing I remember. Listening to it finally, and finally being won over. Not to say that I was turning my back on my past, but that I could be much more open and that there were good things to learn.

O'Hara: Did you ever participate in any of those demonstrations?

Stothers: No, I never did. The only thing I ever did was violate the curfew once. There was curfew in '68. This was just when I was leaving. You have to remember that '68 was when Bobby Kennedy was shot after winning the California primary. We had been sitting in the International House in the Great Hall watching the returns. So we saw a lot of that political action on television there. The city here was in turmoil. When I went home to Canada in early July there were police on the rooftops. I had gone to dinner with one of my friends; he had come and picked me up at I-House and we went to this place. We had to be off the streets by eleven o'clock or something like that. So it's after eleven and here we are tooling around in this little Volkswagen Beetle. That's the closest I ever came to being in trouble [chuckles].

Even though it really changed my life a lot by being here, for the most of the time that I was here I was in a manual wheelchair and I was unable to really push myself any distance. If I was in an area even like the International House, it was

very tiring for me to push myself from my room to the dining hall or anywhere else. It was not an easy task. So if I wanted to go anywhere I relied on other people to get me there. I didn't have an attendant. In fact, if I had had an attendant life would probably have been a lot easier because I spent a lot of my effort and time arranging for somebody to pick me up at a certain place or take me down to class and bring me back or to meet them somewhere. There were no cellular phones in those days either. When the weather changed it could be a real problem.

Freedom of Power Wheelchair

O'Hara: Did you ever think of using a motorized vehicle?

Stothers: I did. One of the things that happened was I began to look at those in 1968. Power chairs were a new idea at the time. I got some money from the Women's Canadian Club to help buy a power chair. They made a donation to help me get a power chair. I don't know how that happened, because I didn't ask them for the money. I think somewhere through the auspices of the I-House it happened. So I ordered an E&J power chair--the first one. It had one battery. I don't know if you remember those, but it had one battery on it.

This was like the fall of '67. It was like October or something when I ordered it, and they said I would have it within three weeks. Well, February came and I didn't have it. Every time I called up they'd say it would be a little while longer. Finally I just blew up and I wrote a three-page single-spaced letter to E&J and I said, "If you're going to tell me it's six months, I may not like it but I'd live with that. But don't keep telling me it's going to be a little here, a little there, it'll be here next week and then something happens so it's not." I was really unhappy and life was hard enough without them adding that kind of burden to me. So I sent this letter to the president of E&J, registered special delivery. That was like a Monday or Tuesday that I mailed the letter. On Thursday or Friday I got a call from the west coast sales manager saying that my chair would be delivered on Tuesday, and it was. That's when I got my first power chair.

O'Hara: So you had a power chair before you left Berkeley.

Stothers: Yes.

O'Hara: What gave you the idea of getting a power chair?

Stothers: I think some of my friends talked about it and said I should do that, and we tried out some. Somebody had seen an ad for a chair. It was like an easy chair, but it had little wheels on it, but it was motorized [chuckles]. We got this chair and we tried it. I had to be lifted into it because it was not an accessible chair. I thought, "I'm going to go down the hill on Bancroft on this thing?" It was very scary.

O'Hara: Where did you find this easy chair? A local vendor?

Stothers: One of my friends saw it advertised in the want ads or something. It got to the point where they were saying, "Listen, we're going to do something about this." [laughs]

O'Hara: You didn't see any of the other people that lived at Cowell [Hospital] in power chairs at that time?

Stothers: You know, I didn't. It was not until after I got mine. Maybe I did. Maybe I did see somebody, and I think Ed [Roberts] was there and he had the motorette. I was starting to think that maybe I ought to get one, too. He kind of put me off the motorette because if it gets wet or you go through something wet you lose control or it spins out. That could be a problem; I didn't really want that to happen. Then I found out about the E&J because I had an E&J manual.

O'Hara: Did it make a difference?

Stothers: It absolutely made a difference. It was total freedom. I was able to go out and go to class by myself and come back. Then I was beginning to do some hardcore work because I was coming down to the end of the period. I don't know if it's changed now, but you could do written exams for an M.A.; you didn't have to do a thesis. So that's what I was doing; I was studying for that in the library. I would go down in the morning and study. I would come back at lunchtime and have lunch, and then I'd go back in the afternoon and back at night. The battery would run down and then die. I was taking those hills; it was very hard. That was kind of frustrating. But still, to be able to do that on my own was exhilarating. In fact, that's when I really was able to go down to Telegraph Avenue by myself. When you're in a manual, depending on other people to take you here and there, you make it count. So you don't just want to say, "Oh, let's go down to Telegraph Avenue" or go down and have a beer or something like that. If somebody says it to you it means, "Okay, I'm happy to do that." But I don't want to initiate that because I may need you to push me

to class tomorrow, and that's what I'm really going to need. So I felt much more at ease about asking people to go.

O'Hara: How much did that have to do with your overall feeling of being liberated?

Stothers: A great deal. That really changed my life. That one acquisition changed my life because it made it a big difference so that when I went back to Toronto after graduating it made it possible for me to live on my own really independently. I still had to take a different kind of transportation that would take a power chair, as opposed to a taxicab. But I could get out and around. I could go shopping by myself. I could have my own apartment, which I did, instead of a rented room in a hotel. I could go and do things and move around. It changed my life. I think that I spent a year and a half here getting psychologically ready to do that and then the power chair plugged it in and made it go; I think it all ties together.

"Frightening" Cowell Hospital Program

O'Hara: You said that you had occasion--once at least--to meet Ed Roberts and John Hessler. Did you go to Cowell Hospital?

Stothers: I think I first met John on campus before I met Ed. He told me, I think, that they had this setup in Cowell Hospital. I thought that was kind of interesting, and he invited me to come by. But I didn't go. Then I met Ed, and he also said to come on by. I did finally do that. I went to visit and I thought, "This is not bad." But it reminded me of too many other places I had been in unwillingly.

O'Hara: What did it look like to you?

Stothers: It was very medical to me.

O'Hara: It was a hospital, to start with.

Stothers: It was a hospital. And it was chrome and curtains and all those things. They were hospital rooms. I think that they were making them their own, but if you take a hospital room and you make it look decorated with your stuff--your posters and things like you would do your college room--there's something very frightening about that. To me there was something very frightening about that.

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O'Hara: That's a very interesting observation that a decorated hospital room is frightening.

Stothers: Well, because I had spent so much time in hospitals or rehab places or whatever, it's almost like saying, "This is permanent." I guess it would be almost like you're going to live in an institution, even here in the heart of this great university where there's so much life going on around you, this is where you come home to. That bothered me a lot. I guess I thought that that would be a future I wouldn't want. Partly I think it is since I had been in hospitals and rehab places that I had spent time which was limiting because I couldn't get out on my own or do anything. But I went to the university and I was just one of the people, even though I helped set myself apart there. I felt apart, I probably was, but also I did it to myself. But then I worked, I lived in an apartment hotel, and there were barriers everywhere. But on the other hand I felt I was really part of the world. This struck me as being really removed from the world, in a way. I have a hard time articulating it. I feel that even now when I talk about it--I have that sense of it. I was living up at International House, I had this great room, and the setup I had was working pretty well--with all the problems of getting around and what have you--but I could get into bed at night and I would never put the blind down because I could look out and I could see Alcatraz and the Golden Gate Bridge every night. I could turn the radio on and listen to great music.

Maybe this was part of it too. I'm not sure where the timing goes, but I'm sure it feeds into that feeling that I feel. I had a relationship here. Over time I fell in with a couple of people, especially near the end--this would be in '67 or '68--with a woman who was also studying Asian history. We started spending time together in the library or whatever. I had a phone in my room because I couldn't use the pay phones. So I had my own telephone in my room. It got to be where we were talking and here I am almost twenty-eight years old, and she's in her twenties, and I'm talking to this woman for a couple of hours every night. I felt like a teenager.

I can't remember what it was, but she had some event in her academic career that she passed some hurdle or whatever. I took her on a date. I can't remember if we went somewhere but we came back to I-House where they were showing a movie that night. We went to the movie, and I held her hand; that was really an extraordinary thing for me to do, given my past and the way I behaved. She was very responsive. Then afterwards

we went up to my room because I took her up in my freight elevator and down to my room, which is totally against the rules. We opened a bottle of champagne which I bought for this occasion, because I knew that she had done this thing. So we drank champagne and turned out the lights, looked out at the beautiful sights, and she spent most of the night. It was a very nice relationship. The funny thing is that in the end I was going home, I was leaving, and she was going her way. I was trying to find a way to get a job to stay here. I was unable to. I felt badly that I perhaps was walking out on her; I didn't want her to feel that way at all. It was just great while it lasted.

O'Hara: Is that part of your liberation?

Stothers: That was part of my liberation too. I believe that she's still around here somewhere. She married a guy who was a Japanese history specialist. He was a nice guy too. I came back a year later after I graduated, partly to see her. I didn't know this at the time--I also learned that you can't go back again. When I left here we were all right here. But we were very far apart--not just this woman, but everybody--a year later. I mean, times move, and a year makes a big difference in people's lives. I stayed here a couple of days and man, I was anxious to leave.

I flew from San Francisco to Georgia to visit with another person I had stayed in touch with, who had been here too. That was fun. Then I went back to Toronto.

O'Hara: You were doing quite a bit of traveling in those years.

Stothers: Yes.

O'Hara: Was it a little bit easier than it is now?

Stothers: It was, because it was so unusual for people with disabilities to be traveling. I was traveling on a manual chair. They always would--especially if they were at all late--put you on first class because it was easier for them. But I was drinking then too, so I would be getting drunk all over the place too. I was not so happy, I think. But hey, it was free.

International House was a very interesting place, too, because there were other people there. People with disabilities--it was one of those things that you're always a bridesmaid and never a bride--I guess that kind of sensibility is that women tended to treat me as a brother, even if you expected some sort of interest in a woman--in fact, I became a

father confessor for a number of women in Berkeley--at I-House particularly--who would often spill tears in my room because of their love lives and things like that. It was very interesting. The people I'm thinking about may still be around. One of them married a professor of anthropology. Another one I think might work in the library, although I don't know that for sure.

O'Hara: Let's go back to John Hessler for a minute. Do you have any recollection of him, what he even looked like?

Stothers: Yes, I remember that he was big.

O'Hara: I would suspect that he was enthusiastic about the program in Cowell Hospital.

Stothers: Yes, he was enthusiastic, as was Ed. This was a great opportunity for them, that they were able to be at Berkeley and go to school and study and have freedom that they would never have anywhere else. I'm sure for them, stripped of the stuff that I brought to it, it was a great idea. It basically was the beginning of the independent living movement right there, in a sense. The idea that you could find a place, whether it's in a hospital or in a house nearby where you could go and create a situation of supports that allowed you to have opportunities that other people had is a marvelous thing. In a sense, I did it the hard way. Maybe what they did was the easier way.

O'Hara: Given the fact that you could get yourself out of bed and dressed--maybe it took longer, I don't know--I'm not aware that any of them could. Do you think that's a factor in why you wouldn't even think of going there? Is that part of it?

Stothers: I think probably it might well be. I was doing it in a different way then, and it worked for me. Despite all the problems it worked for me. Other people had problems. People without disabilities had problems. But it's really interesting: you might say in one sense it's a difference between individuals and community. Here I was doing it on my own, doing it my way, and that's all well and good to a certain extent, but it was an individual thing and it was not connected to other people with disabilities. That might have been part of it too, that I wouldn't want to be ghettoized in that sense. I was beginning, I think, at Berkeley because of all the changes that were happening in my life--a) the power chair that came along, and b) the environment and relaxing the bonds on my mind or spirit--to be more open to other things. I began to be more open to other people with disabilities, so that when I did

go back to Toronto I was ready to positively respond to other people with disabilities and make connections that I would have avoided in the past. Maybe at Berkeley there was still that sense of denial that I'm not like "them," that I don't need to be in a hospital. The idea of living in a hospital was very difficult for me to deal with. Part of that idea might have been just being with other people with disabilities.

O'Hara: Did you see them on campus? I know you said you didn't see Cowell people, but did you see other people on the campus with disabilities?

Stothers: No.

O'Hara: They were a very small group.

Stothers: Yes. All that happened later.

O'Hara: By 1968 there had only been maybe eight or nine altogether so it was a small number.

Stothers: It's amazing when you think about it, that I got here. Given how the university was dealing with Ed and John and those people and beginning to accommodate them, about the reluctance of trying to make that work, to have somebody like me blow in from out of the country is really amazing. I didn't hide the fact that I had a disability or whatever.

Canadian Editor at Toronto Star, 1968-1978

O'Hara: You said when you went back to Toronto you were more open to associations or meeting people with disabilities. What happened?

Stothers: By happenstance I moved into an apartment building. I stayed with a friend of mine, first of all, who was the fellow at the Globe and Mail who has just recently retired from there as the rewrite man. I moved into his house with him and his wife. I lived in their dining room for six months because I was looking for work. I could not get a job. Things were just really tight. The Globe and Mail didn't want me back. I tried all the newspapers in town, I tried all the radio stations, the TV stations, advertising agencies. I really was at my wit's end. One of the things I did at the time was take the Foreign Service Exam. I thought, "I've got to do something." I have

this degree now; it might be useful. So I took the Foreign Service Exam.

Finally in December of '68 I got a job at the Toronto Star because of my friend with whom I lived, he had a friend who was the chief of the copy desk at the Toronto Star, and I had met him myself years before. They invited me in for a tryout and asked me whether my disability would be a factor. The question they had after interviewing me, the one stumbling block that the managing editor saw was, "Do you have the stamina to do this kind of work?" Well, a reasonable question, I suppose, if you want to ask that. So I said, "Of course" [laughs]. What am I going to say? No? So they hired me and I started to work there.

But I did go through the Foreign Service Exam, and I was investigated and went through background checks. I was about to be offered a job, I think, except for the fact that there were some places because of my disability I couldn't go and they didn't want to hire somebody who they couldn't send to those places. I'm happy that I stayed in journalism anyway; it beats working.

This was December '68 that I started working there, and I worked there until April '78, doing a variety of jobs there.

O'Hara: Consecutively or all at the same time?

Stothers: All at the same time. I mean, I spent all those years there, but I did a number of jobs at the Toronto Star from starting on the copy desk. I worked on a similar kind of section I did before at the Globe and Mail which we would now call an opinion section. I wrote editorials for a little while, but not well enough for the liking of the editor in chief. Then I went back and was on the foreign desk of the Toronto Star in the daytime. Most of the work was done overnight, and the foreign editor was there then, and it was an afternoon newspaper so anything from nine o'clock on I was in charge of. That's when Watergate was going on, and Watergate was a foreign story. It was a great time. Watergate was a great story for a newspaper person. I had a great time during that. I did that until '76 or '74. Then I went to the city desk as an assistant city editor and did a number of jobs there.

This was a point where I was beginning to be more of a manager in the newspaper business where I was running a desk of other editors or other reporters and being in charge and making more decisions, which was pretty interesting work. But it was difficult because I was still in this mode of--it's not easy to

change the way you think about yourself. When you have a lot of doubts or not much confidence about it--a lot happens on instinct--but people kind of exude a kind of sense that people pick up on, I think. I presented a pretty good positive face, I think.

It was a busy time, but I was drinking a lot during these years too.

O'Hara: Did it affect your work?

Stothers: I don't think it affected my work but it certainly affected my life. It was not good at all because I did more drinking than not drinking off work. I wasn't really to the point where I missed work because of it. I would come in with a hangover sometimes, but I would not not come in. There would be days when the van came to pick me up and it woke me up--I was paying for a private van service to take me to work--so it was a scramble to get up and get out the door [laughs].

One of the things the Toronto Star did for me--it took me a long time to really realize that I was valued and not pitied, to try to make that distinction. They couldn't give me a raise for some reason. You know how businesses they are; they won't give people raises or whatever. When I first went to work with them, after I had been there a while and they wanted to pay me a little more money but they said they really couldn't do this, I said, "Why don't you pay part of my transportation costs?" So they said they'd pay half of my transportation costs, which was like twenty bucks a week because I was taking cabs. Over the next several years, as I started using the van service, the costs of that was running \$300 a month and they were paying it all by then. They were paying \$300 a month to get me to work and back. That's really pretty amazing. And in the end, after I had bought a house in Toronto, I went to them and said, "Look, you're spending this amount of money a year for transportation for me. Why don't you just buy me a van?" They thought about that seriously. In the end they came back and said, "We can't buy you a van because we're a public company. We really can't do that. But we can make you an interest-free loan to buy one." So they gave me an interest-free loan to buy a van. It was \$5000.

Action League for Physically Handicapped Advancement

O'Hara: I noticed that you mentioned in your résumé that you had directed or supervised an examination of independent living in 1972. I'm curious about that.

Stothers: That article was actually in 1970. When I came back to Toronto I moved into this apartment building in downtown Toronto that was relatively accessible. I discovered by happenstance that there were at least two other people who were wheelchair users in the building. One was a paraplegic named Bill Owen who was from the maritime provinces and was trying to work on a Ph.D. in English and teaching at Ryerson Polytechnical Institute in Toronto, which has become a full-fledged university. He's still there, having gotten his Ph.D. finally too. He was living in an apartment there, and he was a really funny guy and kind of a typical maritime guy. We became friends. There was a woman, a post-polio person, who was living on the ground floor in her apartment. I didn't know her very well. Ultimately she and Bill got married after I had moved out; I had bought a house down the road.

Bill and I were friends during this period, like in '69, '70, and '71. He had heard about this group called ALPHA, which was the Action League for Physically Handicapped Advancement. We talked about some of these things and I thought, "Let's go check these people out." So we did.

I was working at the Star, which meant that I was working daytimes, so I had evenings free. I was often finished by four o'clock in the afternoon--I was getting home. We found out about this group when we went to visit them. These were people who were living in a home called Bellwoods House. Most of them, the leadership mainly, had CP [cerebral palsy]. But there were people with a variety of disabilities, and it was an institutional setting. It was not quite so hospital-like as Cowell Hospital, but it was an institution with rules, and these people were young adults who were pissed off about the rules. Not only about the rules of the house which they struggled against all the time, but also against things in the city. These basically were people who had been marginalized all their lives, and because of their disability they had not been given good educations. They were people of normal or better intelligence, they were very bright people, and they were not afraid about speaking their mind. I would marvel at these people because I kind of retreated into myself because of my disability and really felt this "oh, pity me" internally.

But these guys were kind of in your face. I thought it was wonderful; I thought they were great.

O'Hara: Who were they speaking out to? Who owned this house?

Stothers: I think it was a nonprofit entity, if not the province.

O'Hara: Not owned in any way by people with disabilities?

Stothers: No. The situation in Ontario at that time was all organizations that dealt with disability were run by non-disabled people.

Anyway, we got together with these people and we listened to their complaints, and we were kind of taken by them, Bill and I. The difference was that we empathized with them. On the one hand you have these six or eight people at Bellwoods, and they found a meeting room in a local community building like a library or something a couple of blocks away. That's where the meetings were held. But these people from Bellwoods were largely unschooled but were quite bright and had wonderful ideas and no inhibitions about raising them. Then you had Bill and I, who of course had educational backgrounds, training, were articulate whereas they were not well-spoken. In a way it became a good mix.

There were no curb cuts in the city, and we thought, "We've got to have curb cuts for wheelchairs." This was the first thing that we undertook, and it was the early seventies.

O'Hara: How did you even come up with the idea of curb cuts? Had anyone seen them elsewhere?

Stothers: Other people had seen them elsewhere. We thought, "Why couldn't we do something like that here in Toronto? It ought to be done here." What we decided to do was to find out why shouldn't we do this if it sounds like a reasonable idea. These people from Bellwoods were really pushing on it. Basically they had all their days to do what they wanted to do; they were without jobs to work on. They had time. We organized this and went to city hall. I'm not sure but they may have gone to a city council meeting and started demanding this. They referred it through the city staff--nobody was going to make a decision at a city council meeting to do something like this; they didn't know what it was all about--so they referred it to city staff.

What happened was that we worked on the city bureaucracy and showed them designs, because we had found designs, and they

came up with designs for curb cuts. Then they came up with all the objections as to why they couldn't or shouldn't put curb cuts in in Toronto. We listened to the bureaucracy do that, and we listened to all their problems with it. Then we answered all those problems. So when it went back to the city council they approved it on the recommendation of the bureaucrats. Bureaucrats said, "This is a good thing and we can do it." So it happened. Suddenly they just started appearing. They decided that right off the bat they were going to put money in the budget to do them, and anytime they changed a curb or a sidewalk they would put them in. It was a great policy. This group of no more than ten people got this done. It was remarkable.

Our meetings would be ones where we would discuss a lot of these other issues, not only curb cuts but the problems with transportation and the problems with housing--a lot of these people were living in Bellwoods because they needed assistance to live independently. The whole notion of attendant care was certainly vague at best at the time. That, plus the discrimination that they encountered, this one guy, John Kellerman, who was a very talented guy but was--

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Stothers: I was talking about a friend of mine whose name was John Kellerman, who had fairly severe cerebral palsy. He was a little difficult to understand but not impossible, but often was taken for being drunk in public places and was really hassled quite a lot. He tended to be an "in your face" kind of person anyway, who at some point decided that he was going to let it all be--nobody was taking him seriously anyway, and therefore he was going to be as outrageous as he wanted to be, and he was great at it. He ultimately ran for mayor of Toronto at some point, and lost. He has since died at a young age.

The confidence that this curb cut thing did for people's lives was just amazing in this group. We started talking about issues, of transportation, of housing, of employment, of education. That's what really led me to propose to the Toronto Star that this was an issue that affected a lot of people--the disability issue. We had been picking things up from DIA [Disabled in Action] in New York and elsewhere that things were happening out here. We thought we should really look at Toronto. We should look at the transportation systems, look at attitudes. In fact, I have a page of this; this is one of the things I should give you. I wrote a column about language and attitudes, and we looked at housing issues and transportation and how it affected people. I can't remember the day of the

week it ran, but it was a full page inside the Toronto Star. It was really pretty well done for the time. It was amazing.

O'Hara: You had this idea that there was a lot going on and you proposed an article to the Star. Did you actually write the article yourself or did others do the writing?

Stothers: I think there were three or four pieces. I can't remember exactly. I wrote like an opinion piece, one column down the side, basically talking about how attitudes affect people, that attitudes are the biggest handicap. "Handicap" being the word of acceptability or being "PC" [politically correct] at the time. Having been at the Star for two or three years at that point, people knew the obstacles that I had to deal with. At one point I was coming into the Star building and I had a blowout with my front caster. I had to call my wheelchair repair people and they came out and changed my tire in the office while I was on deadline working. They took a picture of it and put it in the paper.

It was that exposure to my reality that I think made the Star open to try to look at something going on in the community and try to get a handle on it. I don't think it was something that necessarily really stuck over the years, but I think that they did it, and they were open to it, and they decided to deal with these issues. There was an openness there to try to deal with that, and they really did. They put effort into it and devoted a lot of space to it, which is pretty unusual because space is very precious.

They assigned at least one or two reporters and some photographers to it, and I helped set up and find the people. They found some others that I didn't know about, too. There's this kind of push/pull on it: I'm still trying to maintain a position of some objectivity or detachment as a journalist, from being too much of an advocate and being involved, but that was okay. They went with it, and I referred them to people who referred them to people, and I was able to write a piece of my own that fit into it. And I didn't edit the copy. It came out pretty well.

Awareness of Independent Living, 1970

O'Hara: Were you using the term "independent living" at that time?

- Stothers: I don't think we said "independent living," but we talked about the concept, that people had the capability to live independently but they were either restricted because housing was so full of barriers or transportation barriers were so terrible. People couldn't get transportation to get to work, to have a job in the first place. Health care at that point was not really an issue because universal health care in Canada was available then. So health insurance wasn't really a big issue. But it did highlight some of those problems as affecting a lot of people and not just specific issues on people. We had talked about living independently and being free and able to live your life as other people do without necessarily using the term "independent living."
- O'Hara: Did you use some of the ALPHA members as examples? Were they local examples?
- Stothers: They were all local examples, and they were not necessarily ALPHA members, no. They were people who were in the community.
- O'Hara: Were you talking in the article about decision making by consumers at that point?
- Stothers: No, not really.
- O'Hara: What was Judy Heumann doing at DIA that attracted you to talk to her?
- Stothers: We heard about DIA, not about Judy. It just so happens that Judy was one of the people we talked to there. I only remember that because later on I met her and talked to her. I mentioned that to her about how way back when we had done that. I think we had talked to some other people now, and I can't remember their names, but they were beginning to do things in New York and make waves a little bit and we were trying to do in Ontario. It was pretty exciting that you could find that. It was a slow growing thing.
- O'Hara: Was Phyllis Rubenfeld involved by any chance?
- Stothers: Not that I remember then.
- O'Hara: You said you had talked to the Berkeley people after you left-- or did I misunderstand?
- Stothers: No, we knew about some of the stuff that was happening in Berkeley.
- O'Hara: How did you know that?

Stothers: We may have heard that from DIA, about things in Berkeley. I'm trying to remember how I did know. I can't pin it down more than that.

O'Hara: I'm interested in that time period, because 1972 is very early in the Berkeley movement. CIL had just started that year. The formal program at the university started in 1970, so I was just wondering who there was to talk to at that point, not just in Berkeley but anywhere.

Stothers: It might have been just the idea that something like CIL had been founded, that a real center for independent living had started. I do remember telling people in ALPHA and in Toronto about the fact of people like Ed living on campus in a hospital and being able to go to college that way.

O'Hara: Do you have a copy of that article that we can put in the archives?

Stothers: I do. The interesting thing I was going to say about that is that there's no doubt whatsoever in my mind that it was my period here in Berkeley that changed me, that I basically became an advocate in Toronto. That's where my activism stems from. It didn't exist before, and it didn't exist here. I had nothing to do with the movement. It wasn't that my activism didn't come out of the independent living movement here; it came out of just the culture of Berkeley in that time. I was opened up in a way so that when I went back I was able to be different. It's really amazing; it surprises me even now to see myself doing all that stuff.

We put on a transportation conference. The TTC, the Toronto Transit Commission, ran all the transit and the subways in Toronto. This guy was a real mossback. His name was Karl Mallette. He was the head of the TTC. He said people in wheelchairs should not come downtown [chuckles]. This was in the seventies. We were outraged. We managed to get some money together, and we put on a conference in a downtown hotel on transportation issues. We invited people from all these different agencies and just aired the issues. It turned out really very well. It didn't immediately change anything in the city, but I think it did lay some groundwork for the development for what they call "WheelTrans" in Toronto, and they still have somewhat of a paratransit system. The buses are beginning to get accessible.

They are finally even thinking, as they expand the subway system, to put elevators in. We proposed way back in the early seventies that whenever they build on a new station or renovate

an old station, put in an elevator to provide accessibility. Because they didn't want to do that and they didn't want people with wheelchairs troubling them at all, they said it would cost \$15 million and that they couldn't do that. It was redefining the issue into cost terms, that it would cost \$15 million at that point to make all the stations accessible. It was totally out of line. So they weren't going to do anything. Because of that kind of attitude, it's only now in the past five years or so that they've begun to deal with that issue. They lost twenty years. People continue to fight. I've been gone from Toronto for twenty years. They now have ILC's [independent living centers] in Toronto. There are many more people being active. I think they don't probably remember ALPHA at all; it's a whole new generation.

I mentioned before that all the agencies that dealt with disabilities were all run by nondisabled people. When we tried to say that there should be people with disabilities on the board of, say, the Canadian Paraplegic Association, people were outraged at the thought of that idea. They just thought it was a total conflict of interest for people to be that way. Easter Seals, March of Dimes, all these agencies, just thought it was a terrible thing to do. We advocated hard for it--Bill Owen and I were the faces in a lot of this stuff--because we were the most articulate. We became known as the Two Bills. Actually, we had heard that at one point--I guess this is a measure of our impact and effectiveness, too--a national organization that dealt with rehab and disability started spreading rumors to the effect that we were mentally unstable.

O'Hara: Who was this?

Stothers: These nondisabled people who were part of these big organizations. They tried to undermine us by spreading rumors to that effect. We laughed, but when you think about it they were so threatened by what we were doing. It didn't seem like a revolution to us; it just seemed pretty obvious.

O'Hara: Was there anything else, while you were in Canada, that you were aware of in other cities?

Stothers: Not at that time. I think that there was very little going on. It was only just the beginning. Just like here, talking about the stirring of things, ALPHA was the stirring of that kind of stuff in Canada, I think.

O'Hara: I was going to ask you why you were appointed to the mayor's--well, let me ask first: what was the mayor's task force on disabled and elderly?

Stothers: There was an alderman named Ann Johnston in Toronto who had empathy over the curb cut issue. We at that time proposed that there should be an organization that would advise the city on issues and concerns affecting people with disabilities. They independently came up with the elderly side of it. I think that is a fairly common kind of grouping in different cities. I think it happened in Chicago as well, although ultimately they split it in Chicago. They had meetings once a month in Toronto in city hall, and very often Anne Johnston was there. She was pretty good on some of these issues, too. They understood, and they were trying to work out what they could do.

It's not uncommon in journalism--to sidestep a little here --not to be allowed to participate in outside organizations, the reasoning being that if anything happened and you were tied up with a group that came into the news or became controversial for any sort of reason, the newspaper could be accused of bias because of your participation. And you can argue both ways on that because publishers are part of organizations all the time, but that's different.

O'Hara: Same thing with the university not lobbying. We as employees couldn't lobby.

Stothers: Right. But they understood that it was different for me, that the issues involving disability were such that it was okay for me to be part of ALPHA and that I could be on the mayor's committee.

O'Hara: Let me go back to ALPHA just for one second. Did anything develop further in ALPHA? Did that ever become a group or did it disintegrate?

Stothers: It fluctuated. It never had more than fifteen members. After about two years of this--we had gone through the curb cut issue and we went through the transportation conference--it ebbed and flowed a little bit. But it reached the point where Bill Owen and I felt that there was an increasing deference to us--

O'Hara: In the group?

Stothers: Yes. That people were beginning to not want to do things or say things, that they always looked to us for leadership. We thought that that was wrong.

III INDEPENDENT LIVING MOVEMENT IN THE UNITED STATES AND
CANADA, MEDIA DEPICTION OF PEOPLE WITH DISABILITIES, AND
MAINSTREAM MAGAZINE, 1977-1999

[Interview 3: March 14, 1999] ##

Toronto Mayor's Task Force on Elderly and Disabled

O'Hara: We had started to talk about the mayor's task force on elderly and disabled the other day. I wonder if you would just briefly again describe what that was.

Stothers: The mayor's task force was set up in response to some of the issues that had been raised particularly by people with disabilities, through ALPHA. They had been raising questions about curb cuts and then started talking about transportation issues. The alderman who was responsible was Ann Johnston. She was the person on the city council that we had worked with in trying to achieve some of these goals, especially around curb cuts. She, I think, worked on the mayor, who was David Crombie. He also was a fairly open and new mayor and was looking for new ways to be inclusive of people. Ann, working with him, was able to establish this mayor's task force which nominally belonged to the mayor and reported to the mayor. It really was this one alderman, Ann Johnston, who was in charge of it. She put it together with some of her staff people and had monthly meetings, I think, in city hall, at which we discussed a variety of issues that might affect people with disabilities in the community. She expanded it to include the elderly community as well, because she had some contacts and had worked in that area. That's basically what it became, as a way of raising issues with the city, that the city might take some actions, again, on curb cuts or some physical aspects.

O'Hara: And it started as a direct result of the ALPHA group?

Stothers: I think there were some other pressures going on, and it was the time--it was the early seventies--that people were interested in some of these social issues regarding the elderly, and then people with disabilities came along and started raising their side as well. They thought that this was a fairly good idea to establish something like this because a lot of these people were new on the council. There was a new mayor who was an outsider who came in; he wasn't one of the traditional pols. Ann Johnston also was a new alderman. There was kind of like a fresh breeze coming into city hall. They were looking for ways to be much more in touch with different communities, and I think that that's what happened. Over time I'm not sure that they really did all that much, but they provided a forum for people to talk about issues. I think people felt that they were being paid attention to and somewhat empowered and being recognized that they had issues worth contemplating. I think that that's really how it got going and went on. It may still be going on.

O'Hara: What period of time were you on it? Do you recall?

Stothers: I was involved in the middle seventies. Because I worked at the newspaper, the newspaper--like many newspapers--had policies about participation in outside events because if I, for instance, was involved in some group that would become engaged in any sort of public controversy and it was known that I was a member of the group or held any sort of office, the paper could be accused of biasing its coverage because of my connection with the group. That applied to all members of the staff. I wasn't being singled out in any way.

They recognized in Toronto, and later in San Diego, that these were issues that intimately affected my life as well as the life of a lot of other people in ways that some social clubs or other organizations that nondisabled people might contemplate belonging to weren't the same. There was a distinct difference here. Therefore, they said I could do this. It may also be that they thought it was a charitable do-good thing that really didn't matter anyway [laughs]. It's like motherhood and apple pie--who could ever really get upset about things regarding disability? This was a time when these disability issues were not very prominent in the community.

O'Hara: Did you stay on the committee through the seventies?

Stothers: I did until I left the paper. I very often was unable to go to meetings, which were always held in the daytime when I was at work. So my attendance was irregular.

White House Conference on Handicapped Individuals, 1977

O'Hara: In 1977 you attended the president's committee--what was the name of it?

Stothers: It was the White House Conference on Handicapped Individuals, which had been in the planning stages for a long time--a couple of years. It was a very significant event that had representation from all fifty states. I'm not sure exactly of the process involved, but I think that it involved a lot of local activity, choosing people from local communities who would go, representing states--it was almost like a political convention in a sense about having a delegation and choosing members of the delegation that were--I'm not sure how they were represented or not.

We found out about it in Toronto fairly late in the game, actually. But when we did hear about it we thought this was really something interesting, and we probably ought to go and be there. I contacted the people who were putting it on or found somebody to talk to and I asked whether I could come as an observer. They said that would be fine. I couldn't come as a participant because it was strictly U.S. centered. Then we went to the mayor's task force and said, "Look, this is something really important going on here. This is going to be a national U.S. meeting on disability issues, and we ought to be there." It was the end of May 1977, it was just at the time when the Carter administration had come into office, and 504 was a big issue, and trying to pry those regulations out.

O'Hara: Had you known anything about those regulations?

Stothers: Only a little bit. I had heard about the protests going around the country, that people were really pressing on it, and then the sit-in was going on about that time as well.

O'Hara: It ended on April 30.

Stothers: It seemed like there was a lot of stuff happening. So we said that somebody ought to go. They said, "Well, do you want to go?" I said, "Sure." And they gave me \$750 to go.

O'Hara: What happened at that conference, briefly, in terms of perhaps networking or pivotal decision making or moments?

Stothers: Part of it was a celebration because 504 was finally released. There was a lot of networking going on, but there was also a lot of tugging going on because California, which was thought

to be in the forefront of disability rights activity, was regarded with suspicion. People thought that Californians were arrogant and pushy and know-it-alls, and that they thought they knew all the answers. Surprise, surprise. But there were other people, for instance a very strong delegation out of Michigan, where the preferred term was "handicappers," which I think only now is undergoing change here in 1999. There were strong groups from other states.

There was also push and pull between different disability groups. The blind organizations and representatives at this thing were somewhat angry and kind of pulled out and were having rump meetings in the basement of the hotel.

O'Hara: What was the thrust of that meeting?

Stothers: I'm not even really sure. I'd have to say that I came down to this conference and sat in on some things, and it was the sense of energy that I remember about it, and the fact that I had never seen so many people with disabilities together at one time. People had battery chargers plugged into hallway sockets and power chairs were everywhere.

O'Hara: Was it mostly people in wheelchairs?

Stothers: No, not mostly, but they tend to be the most visible. There were blind people there and people with dogs and people with CP. It was a kaleidoscope. But the wheelchairs were more visible, especially the power ones. You could see along the hallways these chargers plugged in everywhere [laughs] because people were running out of power during the day.

O'Hara: Who were the leaders of this White House conference?

Stothers: I don't recall at all.

I went to several workshops, and one was a civil rights workshop. This was a place where everybody was beating up on California. They had come out of the sixties, and there was that same kind of shouting down. It was a very antidemocratic period [chuckles] where people really would try to prevent people from talking by yelling and screaming. There was a lot of hostility and negativity coming out against California and the people from California in this workshop. Actually it was pretty tedious because it was like tantrums.

Future Wife, Cynthia Jones

Stothers: I was sitting back by the doors because I liked to float around at different things. A young woman came in on crutches and there was an empty chair next to me, and she wanted to sit down, and she did. We watched this for a while, we were all sitting there, and I finally turned to her and said, "This is very boring. Do you want to go and get a drink?" We did, we left this madhouse and went to one of the bars in the hotel. This was Cyndi Jones, as it turned out.

I found a bunch of meal tickets. When you came to this conference you get tickets for the meals which were box lunches. We found a bunch of those that I gave to her because she had come from San Diego with Jim Hammitt, who was the editor and founder of Mainstream Magazine. Jim has severe CP and had never really traveled before. Cyndi came along with him. They were really there on a shoestring. In fact, they were not staying in the hotel; they were staying with friends. Cynthia was staying with the family of an Episcopal priest that she knew, sleeping on the living room floor. I, in the meantime, was staying at the Hay Adams Hotel because I had all this money that they sent me down with. I had driven down and was staying in a fancy hotel.

Anyway, we had a drink, and this kind of diverges from this conference a little bit, but that's where we met. I wine and dined her all week long, as it turned out, and took her out on a dinner cruise on the Potomac River. We went to some museums on some off time. The conference lasted like from Monday through Friday, I think it was. Friday I was driving back to Toronto and had asked her to come back to Toronto with me. She declined, saying that she had a responsibility with Jim to go back to San Diego, and that she was supposed to be a chalice bearer on that Sunday and all of this stuff. So I gave her my neighbor's phone number in case she changed her mind. She took off and that was that, I gathered. I drove home and got home on Sunday afternoon. Lo and behold, she was in my living room. She stayed for three days and then went home, and then I called her and she came back and stayed.

As I say, this kind of diverges from the conference a bit, but for me, of course, it was a great conference.

O'Hara: To follow on that track, eventually you were married.

Stothers: That's right. She stayed, and actually she was an illegal alien because she just flew back to be with me. So she

couldn't work. She did some tutoring with some people. She stayed through the summer. She was not sure that she wanted to marry me; I was eleven years older than she was. She thought that I was an old man maybe, and that she didn't necessarily want to do this. We got married December 21, 1977, at city hall in Toronto.

Prior to that, in October, because of my work at the newspaper, I had accumulated almost two months' worth of vacation time. We took like six weeks in October and flew to San Diego to meet her parents and family. We rented a van. We were able to somehow find a van with a lift to rent. We drove up the coast all the way to Vancouver, where my sister and her family lived and where my parents were moving to from Ontario.

Along the way I was looking for jobs because winters in Toronto were harsher than they are on the West Coast. We looked and looked and nothing. We didn't find anything along here, but I had not asked about a job in San Diego because Cyndi didn't really want me to. She was very involved in Episcopal church matters and it was at the time a very conservative diocese. She would have been happy to go somewhere else. In the end, however, a friend of hers suggested I send a résumé to the local newspaper anyway--which I did when I returned home in late October. I received some expressions of interest from the paper, the San Diego Union. It was undergoing a renaissance and a great deal of change. They had hired from late '76 into '77 an extraordinary number of new editors and reporters to turn the paper around, which had been at one time called one of the ten worst newspapers in the country. So there was a big effort to change that.

The editor of the newspaper was Gerald Warren, who was a former deputy press secretary to [President] Richard Nixon and had joined the paper as editor in 1976, I believe. After having contacted me about my résumé, they decided that Jerry Warren was going to be in Washington in January for some meetings and was going to fly to Toronto to interview me. That was a period where they had one of these monster snowstorms that kind of shut down the entire northeast, and he was unable to get to Toronto to interview me. Cynthia particularly could see this window closing, that she would be stuck forever in the cold north of Canada. But subsequently, in February, they flew me down to San Diego for an interview. Leaving the snows and ice of Toronto, it was like seventy-eight degrees and sunny and warm in San Diego. They offered me a job. I had to go through immigration issues, and then I started to work on May 1, 1978.

It was very interesting about immigration. I had been born in the United States, raised in Canada, and I had become a Canadian citizen in my twenties, which the United States never knew. I mean, they don't exchange these things as information. So when I was coming back down here I had sought some advice, and I was told that I should go to the consulate and tell them this story and find out what really was necessary. They told me that I would have to apply for a green card and go through this process.

Subsequently, much later, I learned that all I had to do was come back and say "I'm an American, I was born in the United States, here's my birth certificate, I don't have a social security card--or a draft card--or anything else" and had that issued, and it probably would have gone that way. Because of what they had advised me I wound up having to renounce my American citizenship in order to apply for a green card as the spouse of an American, which was kind of a convoluted thing to do. So I have been an American citizen by birth, and a Canadian by choice, then an American citizen again by going through the process that aliens go through. It's really unusual.

The White House conference really was a pivotal event in the country because it reaffirmed the birth of a movement. There are roots that go back a long way in different parts of the country--for decades, in certain instances. And there have been people with disabilities who had organized themselves into clubs or social groups or whatever. But the politicization happened as a result of coming out of the sixties and that general milieu. But I think that the White House conference was kind of a time when people really began to see one another as having similar views from all over the country, despite the fights that happened, which I think are inevitable in any kind of group of people, in any kind of new movement where people are struggling to find out who they are and what they're trying to do and being at different levels of development around the country. I'm sure these things still go on.

More on Independent Living

O'Hara: Were there any other factors that you can see that made the seventies such a leap forward in this concept of independent living and disability rights?

Stothers: I think part of it is the Architectural Barriers Act was in 1968, and I think that that maybe signified a group of people with disabilities--a small group--that began to push for legislation not only in different states but specifically in Washington. I think that in some ways this movement has always been kind of a middle-down, not a top-down, movement. There really wasn't a broad grassroots kind of upheaval demanding this kind of change; it was a group of people who have been and in many cases still are leaders who are demanding things for themselves and wanting better treatment, that have been able to kind of go beyond themselves and tried to establish this more broadly.

O'Hara: Do you know who any of the people were that came out of that period?

Stothers: I believe Hugh Gallagher was one of the prime movers in that. He was active in Washington at the time. When you see the possibilities of what can happen and how laws can be made, and if you have enough initiative, you can start to work that into your favor. If you're close to any sort of legislator--whether it's a congressman or a senator--people that you work with if you have a disability began to see things and have an understanding of what's going on. It becomes kind of like a personal outrage if you can't get up steps or find a way into a place or it takes you a long time to get somewhere or you can't get into bathrooms because they're not big enough. People who are political, I would think, in a "big P" sense of being involved in the legislative process or whatever, can see that they can make changes to make those things better, that they can look beyond calling in contractors to fix up one particular office or whatever. They can understand that you're going to go other places, and, therefore, maybe there's a way that we should make these things change.

He has a new book out now called Bye Bye Blackbird. I think it's autobiographical about these issues. I haven't read it; I've just looked at the preface, but maybe it will explain some of it.

O'Hara: So you picked up and went to San Diego.

Stothers: Cyndi always says that I went to this conference looking for somebody with a southern California name tag [laughter].

O'Hara: The reason you moved then was because you were married and--

Stothers: And the weather--when I had gone back to Toronto in 1968 I could get out and around the city easily in my new power chair

for all but about two to three weeks in the winter. In 1978 maybe two to three weeks I could get out of the house. There were times when I couldn't get to a van because the snowdrifts were too high, that I couldn't get out of my house. That's an indication that it's time to get out. I thought my options were limited, and I didn't like being cooped up, and I really felt cooped up. A lot of people with disabilities live in that situation now. People who are post-polio are very sensitive to cold. And for Cyndi to stay there would have been very difficult because she walked more then than she does now, but it gets very icy and difficult and slippery. She had a terrible time in that one winter that we were there, and it would have not really worked at all.

Ombudsman for the San Diego Union, 1978

O'Hara: I noticed that you had a variety of editorial positions at the San Diego Union and that you ended up as ombudsman for the readership?

Stothers: Yes.

O'Hara: What was that?

Stothers: The newspaper made a decision many years ago, understanding that readers are not always happy with what goes into the paper and also that the newspaper is not perfect and makes mistakes. Therefore they established this position called the readers representative, who was a senior editor designated to be responsive and to deal with complaints from readers and to evaluate and assess the complaint and make corrections where warranted. The position reported directly to the editor. The person who occupied the job had the authority to talk to anyone in the newsroom to explore complaints and to order corrections to go into the paper, even if people objected, if, in fact, we believe that the paper made an error. That position had been established long before I got there. I was the fourth person to occupy the job. It was the best job I ever had at the newspaper.

O'Hara: Why?

Stothers: Because I had the time to sit and reflect on what we did as a newspaper. In the day to day hurly-burly of newspaper work things do go wrong and you make mistakes, and you try to cover the news and the events of the day by the seat of your pants

trying to get things done. But people do try to do it correctly. It's not kind of "Oh, well," although some people have done that, I'm sure. But people do strive to do it accurately.

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O'Hara: You were talking about readers being receptive.

Stothers: The newspaper has to be regarded as credible to maintain its authority. You have to show to people that you're responsive to criticism, I think. The job of readers representative, as I said, had been going on for some years before then. I was one of about thirty-five people in North America who were doing similar jobs. They have an organization and an annual meeting, and it continues now. In fact, I did the job for about three years. My successor has been there since; that's about seven years. It's a really important job. I really dealt with the public more than I ever had before. In journalism my place had been mostly behind the scenes as an editor, working with reporters and not dealing with the general public per se much at all.

So this was a big change for me, plus the fact that I wrote a weekly column. Before I got there it was mainly focused on summarizing the corrections of the previous week and ones that didn't make corrections and maybe explaining to the complainant what had happened. I took it as an opportunity to talk more generally about journalism and how not only our newspaper performed but other media. I wrote one column about setting people up. There was a local television guy who really set somebody up to be arrested on camera, and I discussed the ethics of this. I really became interested in the ethical issues of journalism and wanted to write about that. Not only about what the paper did, right or wrong, but what it did or didn't do. When you decide what you're going to put in the newspaper you also decide what you're not going to put in the newspaper.

Traditionally newspapers have vast sources of information that come in over news wires, and material that is self-generated. What gets into any given newspaper is probably less than 10 percent of the available material. So there are big decisions about what's important, what gets in and by definition what doesn't get in. I think that people have a right to know the decision making process and how you judge news and how you decide what to put in and what not to put in and the process whereby that happens. Especially controversial things that sometimes appear in the paper and whether or not

that was a good decision or not. And I took the opportunity sometimes to say that the newspaper was wrong in doing this or that, which sometimes did not make me very popular with the senior editors, but they let me go with it.

I had strong support from the editor of the newspaper even if he disagreed with me. He always wanted to read my column before it went in or one of his surrogates would read it, which is good because sometimes you make mistakes or miss things. Everybody needs an editor. They didn't always agree with me but they always agreed with my right to say it, and I thought that was really important. Reporters hated it and never liked to see me coming because it's as if they made a mistake, and nobody wants to be pointed out as having made an error. Nobody likes to be held up publicly to having made an error. But on the other hand, if we make mistakes, we in effect held somebody up to error who is an innocent person in the community. You can't have it both ways. You can't single people out and tar them for something and then not want to correct it because you don't want to be hung out to dry. People constantly--even now--complain that the newspaper, in doing this kind of a job, is hanging its dirty laundry in public. Or washing it in public. That's nonsense.

Media Coverage of People with Disabilities

O'Hara: You said in one of your columns in Mainstream that you were very disappointed that you were never able to get the San Diego Union to incorporate articles on disability. What did you want them to do and why didn't they do it?

Stothers: The newspaper occasionally would do stories about a person with a disability. One of the classic ones that I remember before I became the ombudsman, and it was on the local news section page--a picture of a woman. The point of the story was the fact that this woman who had a disability was getting married. That was it. That was what it was about. I thought this was very peculiar.

O'Hara: Why don't you explain for the benefit of future readers why you think that's peculiar?

Stothers: To my way of thinking people with disabilities do the things that other people do: they get married, they have children, they go to school, they go to work. There are a lot of people who can't do those things for a variety of reasons, but there

are a lot of nondisabled people who do the same things or don't do them for similar reasons. "Newsworthy" means something out of the ordinary or different. The fact is that this was a very ordinary thing to an ordinary person who was a member of the community. The fact is that the people who put that story in the newspaper believed that this was an extraordinary thing, that a woman with a disability would be getting married. It's that kind of shock to their system and surprise that a person with a disability would get married. It had no other reason for being than that, and that shows an attitude among the editors about what disability is or isn't or a lack of understanding about that. Especially when I'm sitting in the newsroom, as a person with a significant, severe disability and I'm working.

O'Hara: And married.

Stothers: And married and living in a house and driving a van. Yet there's this disconnect between not thinking about me and that woman on a par. I was very upset by that and similar stories that very often people with disabilities would be portrayed in a pitying kind of way, "Oh, this poor person," or "This person needs special treatment," or "Aren't they brave and courageous?" or trying to overcome injuries or their disability. And sports stories about disabled athletes tended to be run not on the sports pages--people who, say, race in marathons in wheelchairs are extraordinary athletes just like any other athlete of a high caliber, but they were not covered in the sports pages. Because they had a disability "it's not really sports." When people participated in sports events like marathons, and run wheelchair marathons, that routinely they were not covered in the finishes and stories to wrap it up. Always able-bodied athletes were covered. People in wheelchairs were not included even after I left the paper. A local woman who was a very prominent marathon racer nationally was sponsored by Northwest Airlines, appeared in major national TV and newspaper advertisements for Northwest Airlines. She was from San Diego County. She finished third in the Boston Marathon and was not even mentioned in our local newspaper.

O'Hara: She used a wheelchair?

Stothers: She used a wheelchair. There was no mention of wheelchair winners. She finished third in the year that Jean Driscoll, who won the Boston Marathon like six years in a row setting records--never been done by anybody, male or female, wheelchair or foot racer--never has been done by anybody. Totally ignored. The Boston papers tend to do a pretty good job on this because it's become a very prominent part of the marathon.

Outside of that it's virtually not mentioned by anybody. There's something wrong with the media when we're doing this. And it reflects attitudes about disability in the country, that somehow it's not the same; it's other, it's different, it doesn't count somehow. "Well, yeah, but you gain advantages when you go fast down hills." But you have to go up hills, too, and you lose ground when that happens. People choose to treat people with disabilities that way in the media.

I've found it very distressing, very difficult to counteract. It was very difficult to make people see disability as anything other than an individual issue. To point out that there are programs such as SSI [Supplementary Security Income] that can provide some assistance to people with disabilities but also imposed programmatic and systemic limitations on those same people. Trying to alter those kinds of perceptions in the newsroom was a very difficult job to accomplish, and I certainly didn't do very well at it. It didn't ever really change. I wrote about it in different opinion pieces.

O'Hara: This was different from the Toronto Star.

Stothers: Only the one time when we did that thing in 1990. I was at a higher level, in one sense, at the San Diego Union, plus the fact that I was becoming much more engaged in disability rights issues and looking more critically at the media than I had before. In my own personal experience I found that places where I have worked I have not really had that much difficulty getting jobs there, which is a good thing. On the other hand I think that looking back on it that there has been paternalism involved and limits in assessing what I could do.

Increased Assertiveness

O'Hara: Were you engaged in any disability-related activities outside of work?

Stothers: I think I was becoming more assertive the older I got. In San Diego, because of Cyndi's involvement in finding us a house to live in--accessible housing was very difficult to find. Right from the get-go she had to become, in effect, a real estate agent in order to find us a house because nobody else knew anything about it. When we had met, it was kind of her last stand or last act with the magazine [Mainstream] because she had been there for about two and a half years and was burned

out and was leaving. About the time after we found a house in the early eighties, she went back to be on the board of the agency that published the magazine, which began to fall on hard times. So she became increasingly involved in the magazine, and in fact volunteered to run it for a short time until they could get their funding reorganized and get it back on track. This was in 1982. In 1984 she was still doing this; two months had turned into about two years. Then she burned out again on this and said she wasn't going to do it any longer because nobody was doing anything. She in effect said, "That's it. I'm out of here." Just before we went on vacation they asked if we would be interested in buying the magazine. This was 1984. We decided we would do this. This was the last real vacation we had [chuckles].

While she was doing that from '82 on and being involved in that, it also involved me because of my editorial background and skills; I was pressed into service to help produce the magazine. I had two jobs: I had my day job at the newspaper and came home and worked on the magazine at night on the dining room table, editing and writing and the like.

O'Hara: You really learned about activities and issues.

Stothers: That's right. And actually it was very good because however much I protested it clearly was a great education because the magazine had a national outlook but also had local ties. So we were involved in local issues as well as national issues. It was a very important time in the eighties, and the struggles that were going on. It's another instance where the newspaper allowed me at one point to join the board of the local ILC [independent living center] because they knew that these were the kinds of issues that affected me personally, and they didn't really think it was going to be such a big deal anyway.

The reason I got asked to be on the board--the ILC was called the Community Service Center for the Disabled [CSCD]--is that there was a coup. Some members of the board decided that the executive director was acting in too high-handed a way, that the agency wasn't being run efficiently and effectively. They decided that they were going to dismiss him, and they proceeded to do that. They added new people to the board, of which I was one, not having been very much involved with it at all beforehand and not really knowing too many of the people there. Some of my friends were involved and told me what was going on and what they would like to do. Well, it turned into another throwback-to-the-sixties fight where the people who were dismissed used a maneuver that if you bought a membership in the center you were able to have a vote. So somebody went

out and spent \$2,000 to create 200 new members and demanded a public meeting for the purpose of recalling the board. That meeting occurred, the board was not allowed to say anything; they were basically shouted down whenever anybody tried to answer a question or do anything. The vote was held and the board--of which I was a member--was dumped. So my term on the board was short-lived, and I can't say that I'm unhappy about it [chuckles].

O'Hara: Did the executive director resume his position?

Stothers: The executive director resumed his position and eventually became the director of vocational rehabilitation with the state, Bill Tainter. It was a very political time in the community. As to whether the center was being run well or poorly, who's to say? Obviously people thought that it might not have been run as well as it might be, that the way it was being run was maybe not appropriate. Again, I got involved on the basis of people whom I knew and respected who had asked me to help. It's taken many years since then, in fact, for some people, those wounds from that time have not healed. I'm not one of them. It was a very hard time. The Center, I think, has gotten on track since then. They had a very strong executive director after Tainter left to go to Sacramento: Patricia Yeager, who did a great job and really reorganized the entire center.

O'Hara: Did you ever go back on the board?

Stothers: No. Again, I'm just as happy not to have done that. There are other things to do. There are too many different areas to operate in the community that we all don't have to be doing the same things. I think it's really important for other people to be involved in those issues.

Lectures on Disability Terminology

O'Hara: Another thing I read was that you did some lecturing on journalism and terminology of people with disabilities.

Stothers: Yes, I wrote some columns. I used to get highly annoyed at the use of terminology such as "confined to wheelchairs" or "wheelchair bound." In fact, one of the columns I wrote on this appeared in the Union as my ombudsman column. It was one where [the reporter] referred to somebody as being "wheelchair bound." I got a photo of a woman from southern California who

had been arrested at an ADAPT [American Disabled for Accessible Public Transit] demonstration protesting the transportation industry convention. She was being tied up in her wheelchair in Montreal at this convention. I put this picture in the newspaper and I said, "This woman is wheelchair bound. This is what you say when you say this."

After going to Washington for the White House conference I had written a travel piece for the Toronto Star about accessible Washington. I had signed it at the end with a tagline identifying me, saying that William Stothers is an editor of the Toronto Star, who is liberated by his wheelchair. That's what I did in columns when I talked about language like that or spoke to other groups about coverage of groups and events and how to get coverage and how to speak about people. I did some of those speeches locally in San Diego.

It was very interesting to go out and speak. I didn't do a great deal of it in the three years that I was readers representative, but I did some. Some at schools, and some to some other organizations. It was very interesting to go out and suddenly appear as a person with a wheelchair and have to ask about access issues when you go there or whatever. Kids are really open to hear this and to talk about issues like this. It's very interesting to talk to them about it.

It was also very interesting to go to agencies like the regional center. I talked to staff members there because people tend to feel shut out of the media experience because they tend to get burned by the kinds of publicity they get. I would just try to tell them what I thought were ways for them to successfully reach editors or reporters that would give them the kinds of stories that they wanted or call them when something needs to be publicized.

Disability Independence Day in Balboa Park¹

Stothers: In March of 1992, a group of us were among the crowd at a fundraiser for our local ILC, then known as CSCD [the Community Service Center for the Disabled]. This event had, as one might expect, a St. Patrick's Day theme. Anyway, our group repaired to the bar afterwards, discussing as we always seemed to do,

¹This section was inserted by Mr. Stothers during the editing process.

the state of disability activism in our town and the small number of people involved.

During the course of the talk, I suddenly had an idea. We ought to have a celebration to mark the anniversary of the signing of the ADA. We could use the occasion to try to enlarge the community by getting people with disabilities to come out.

Other groups held events to party, but no one did anything with advocacy as a central focus. That's what we could do around the ADA.

Great idea. But having the idea in mid-March did not leave a lot of time to plan an event and make it a success. The core group of organizers consisted of myself, Cyndi Jones, Betty Bacon, and Royce Hamrick.

We gave it our best effort. We learned that the disabled services of the city park and recreation department held an annual event called Summerfest in Balboa Park (the city's big central park). We talked to them and agreed to join forces. They supplied a lot of equipment and manpower, and a mailing list. We brought in the activist community and energy to get publicity.

The first annual Disability Independence Day in July 1992 was a surprising success with more than 300 people attending and coverage in the local media. We had a march through Balboa Park. We had entertainment and information booths. We learned a lot.

In subsequent years, the event grew and became more advocacy-centered. Justin Dart, Jr., came as the main speaker one year, and Judy Heumann was the main speaker another year. The march in the park grew and became more lively.

Then in 1998, the event was shifted from the open Organ Pavilion area in Balboa Park to the indoor Balboa Park Club. The march was dropped. The entire event seemed to lose energy and steam. Oh, it was fun. We had food and entertainment. We honored the achievements of people with disabilities. We danced.

But the event changed. New leadership has now taken over and it's about time, too. Plans are well under way for the celebration of the tenth anniversary of the ADA. It is still an important event, but success in galvanizing the broader community of persons with disabilities remains elusive.

Attendance reached about 750 one year, but has fallen off recently. The struggle to build community goes on.²

History with *Mainstream* and Suspension of Publication, 1984-1998

O'Hara: What then prompted you to leave the San Diego Union and write for Mainstream?

Stothers: We had owned the magazine since '84. I still was working nights and weekends on it. The magazine was struggling; it's always struggled. It was basically a break-even proposition, but that's because we subsidized it with my salary from the newspaper. We were undercapitalized. We had always believed that if we had money that we might be able to make a breakthrough to really establish it economically. I was also looking for an opportunity to play a greater role in the magazine. In 1992 the San Diego Union and its sister newspaper, the Evening Tribune, merged. The setup was that both papers were in the same building, they were on the same floor, they were separated by a hallway. But the rest of the departments--the production department, advertising, circulation, and printing--were all done by the same operation. So everything was the same except the editorial departments. They decided to merge those for greater efficiency and profit. They offered buyouts to some people. They had a program to reduce the number of staff: they offered a buyout depending on years of service and seniority and all these factors, and some people were terminated to get to the staff level they wanted.

Well, I was very happy with my job. As I said, it was the best job I had ever had at a newspaper. Every job I had, as I moved, was the best job I had ever had. I've been very lucky in that sense. I know that they were very happy with me. But Cynthia and I talked. This was an opportunity that would never come again. If we did this now, I would get a considerable amount of money that we could use to see if we could make the magazine work. If we can't, then we should end it or sell it or do something with it. We needed that kind of energy and push on it. We thought that we had enough money that there would be enough for a couple of years. I thought, "In a couple of years I could probably still go back and get a job at this newspaper or another newspaper or something if it didn't work."

²End of inserted section.

We did it. We had developed the business plan before. The money I got was substantial, but was nowhere near the million dollars we thought we needed to really make this work, for the business plan we had done. But we thought we would have the opportunity of trying to make it work and also to be able to go after other funding sources. We never did find other funding sources, but we did make it last not two years but six years. Also, I went from doing a day job and a night job to only a day job. So that actually did have its benefits.

Exploding Myths, Incorporated

O'Hara: Let me ask you a little bit more about Mainstream magazine. It was owned by Exploding Myths, Incorporated? Do I have that right?

Stothers: Yes. Mainstream first started in 1975. Jim Hammitt started it, and it was kind of a local newsletter. Then it began to grow over time. It was established as a nonprofit run by Able Disabled Advocacy, Inc.

O'Hara: Which was?

Stothers: It was like a nonprofit organization that was mostly funded by the federal government under work training programs.

O'Hara: A local organization then.

Stothers: Yes. It was a local organization. It was kind of an employment training program where they came in and they trained people in different jobs and gave them experience in how to work in a work environment, how to dress, how to show up on time, how to do these kinds of things. They had a good record in placing people. In fact, one wheelchair user who I think is a quadriplegic went on to become--and still is--vice president of one of the banks in town. They did place people and do some good work. When [President Ronald W.] Reagan came to office all that money was cut, and that was in the early eighties. That's when this agency fell on hard times because it couldn't really sustain it.

When we bought the magazine in 1984 we formed a corporation called Exploding Myths. It was our corporation which bought the magazine, and it continues to own the rights to the magazine and the trademarks and everything, and it is the business entity that we now continue. It was named after--

shamelessly I stole it. When I was in Toronto, when I bought my first house in 1973, it was a duplex like a hundred years old, in an area of town called Cabbagetown. It was a row house twenty feet wide and seventy-two feet long. To get to the back you either went through the house or you went around four houses to get to the alley to go around. It was a duplex, but originally it had been a single-family house. I lived on the bottom floor. It had a dirt basement in the front, a dirt basement in the back, and a crawlspace in between.

O'Hara: On your floor?

Stothers: No, underneath. It had these high ceilings--a wonderful old house. But I had some tenants. It was a single mother of two young boys, and she was a community organizer, and I rented her the space. She was an artist as well as being an organizer. She had a lot of socialist inclinations. We were friends and we spent a lot of time together and shared facilities. We mostly ate in my area and cooked downstairs. In some ways I provided some father figure for these boys for a little bit. We formed a collective called the Exploding Myths Comic Collective, and we wrote socialist comic books. This woman drew the comics and we produced them. We tried to sell them. We did about four altogether. It was very hard work to get six or seven people around to write dialogue and agree not only on the ideology but also the wording and the humor and--oh, it was a lot of work. But a lot of fun too. So that's where the corporate name came from, which we thought was appropriate because it really is what we're trying to do. What the magazine is trying to do is change attitudes, to explode the myths of disability.

O'Hara: Who was the audience for Mainstream magazine?

Stothers: What we were really trying to do was to grow the movement. The audience was not the choir of advocates per se. In some ways we tailored the writing of the magazine. The reader I had in mind was somebody who had a disability but who was not connected, who was basically isolated and wasn't aware of equipment that was available, not really aware of commonalities of the disability experience, the positive experiences and the possibilities of living with a disability. People who had problems and who were successful--not that they solved their problems or overcame their disability but lived their lives and had successful lives. Funny things happened to them, terrible things happened to them, difficult things happened to them. But they persevered, and that's the kind of understanding that we wanted people to have, that they weren't the only ones who

were disabled in the world and that there were other people who did join together to work on issues and could make an impact.

O'Hara: Where did you find the audience?

Stothers: That is continually a problem. For any publication that's a difficult thing. We would go to trade shows. The abilities expos that are held around the country.

O'Hara: You went to all of them?

Stothers: Initially it started with one, in Anaheim. Then after a while they added another one in Edison, New Jersey. Later they added others; there are now five, I think. And they've tried others in different locales.

For a while we went to all of them and then we cut back. We know that our magazine is not for everyone; no magazine is for everyone. So we offered a program of three free issues to people. If they signed up we would send them three issues and then ask them to pay if they wanted to continue. That was one way of doing it.

We advertised in mailings. We even went so far on one occasion to put an ad in the Sunday supplements, in those slick coupons, with very little success. Most things that we tried were not successful. I mean, that particular thing was certainly not successful. Other mailings have been more or less productive. Basically we found that most people with disabilities don't want to pay for information. A lot of people are unable to afford the subscription price or didn't think that they ought to have to pay.

O'Hara: Did they tell you that?

Stothers: Yes. We didn't really rent mailing lists, but we tried to circulate the magazine in different ways. For instance, if you were having an event here in Berkeley and you were going to have a hundred people there and you said, "We're looking for anything you could do." We'd say, "Well, we can send you a box of a hundred magazines that you could give out." And they would have a form in there that people could then get three free if they wanted. We did a lot of that kind of salting, if you will, to try to develop subscribers.

The truth of the matter is--as I said at this conference this weekend--if you add all the disability magazines together the total circulation is probably in the neighborhood of no more than 150,000. That's half a dozen magazines. There's

probably a lot of overlap of subscribers as well. Not all our circulation was paid--rarely do you find a magazine where everything is paid. So you would find some people are getting the magazine for free, others are paying for it, and you get different sales offers. We didn't do this very much at all, but big magazines like Time and Newsweek and those kinds of huge circulation magazines often offered magazines at professional rates and student rates and all these different kind of rates so it's sometimes difficult to figure out who's paying what and how much money they're making on it. Again, it comes down to advertising revenue that mainly pays the freight on these kinds of things.

The magazines in our movement, such as the Ragged Edge now and Mouth, which don't have any advertising are dependent on subscription revenue or gifts or donations. And it's very hard to mouth. The magazines like us and New Mobility and Paraplegic News and others really rely on advertising to carry the freight, and it's an expensive business. That climate has declined, and in fact the reason why we ultimately closed the magazine is that there's been kind of a great consolidation among the companies that provide products to people with disabilities. As a result, the whole advertising base is shrinking. Most recently we found a company that was a longtime good advertiser for us--a van company--bought another van company, which was also an advertiser. So instead of having two ads, full-page color ads, you're suddenly going to have maybe one. It's knocked down a lot, and that makes it very difficult to do the kinds of things that you want to do.

In order to grow and to do the kind of work we wanted to reach people with, you have to have money because it costs money to develop circulation. The more paid circulation the better off you are. If you could reach a stage where your paid circulation pays basically for the mailing and the actual printing of the magazine, then you're almost breaking even on that, and that's a pretty good place to be in. Mostly it's a loss leader. Therefore you have to have the money to do that.

When we had first started back in the early eighties we did this business plan that I mentioned, and the projections calling for investment were that in the third year of the plan we would lose \$650,000, and mainly it was for circulation development. But then it turns around in the fourth year and the fifth year, and you then start making two million dollars a year. But you have to have that initial pocketful of change to make it go, and that's just unrealistic in this industry.

The sad thing is that people with disabilities need information, and the kinds of things that we were trying to do were aimed at bringing those people with disabilities into the movement, making them aware of it and trying to exhibit pride in the sense of who we are. Not that you're necessarily proud of your disability but, like anybody, proud of who we are as people, and we have shared experiences that we can derive some value from. There are things that we do as people with disabilities, I think--Paul Longmore has talked a little bit about this--that are models for how people can live in the modern world. We're a very resourceful people and creative survivors. People can learn things from us and the way we do things. That's what we wanted the magazine to show to people.

Part of the problem with our magazine and with most magazines is that people who have a disability who aren't connected to the movement generally don't want to be connected to the movement. If you asked them directly they would choose not to be. They would like to be cured or they would like to be not disabled, and they don't want to necessarily associate with other people with disabilities because it's kind of an acknowledgment of a part of themselves that they maybe try to deny or at least ignore and hope that other people ignore, as I did when I was young. It was a very real thing, and you go to great lengths to try to achieve that.

I drank a lot to do that. Even after having been in Berkeley, which really did change my life and the way I think about myself, really took a long time to play itself out because I continued to drink increasingly heavily until I was back in San Diego. You do it to yourself without knowing it sometimes, and I think that it becomes a difficult thing to turn around. I think it's not an uncommon thing to happen to people with disabilities. I shouldn't project my experience to say that I'm Everyman, but I think that there's truth to it. I've known a lot of people with disabilities who, if they don't abuse substances, find other ways to hide or deny, whether it's overwork or busyness.

Managing Editor and Editor

O'Hara: Your formal title was editor of the magazine.

Stothers: Yes.

O'Hara: How, in practice, did you and Cyndi divide up the work?

Stothers: It was very difficult because initially Cynthia did not really believe that I had much knowledge or the correct attitude on these issues, because I was not so deeply involved. I think that she was somewhat suspicious. When I first joined the magazine I did not take the title of editor because she was reluctant to surrender that title.

O'Hara: In '92.

Stothers: In '92. I was not on the masthead prior to that, because in a sense it would be a conflict of interest to have that kind of title and/or job while I was working for another publication, being the newspaper. So in '92 I became managing editor, which is a lesser job, and she was publisher and editor. She insisted on basically looking over my shoulder and reading everything that went into the magazine to make sure that it was correct and that we were doing the right kinds of stories. Well, that didn't last that long; I changed that within a year. The titles got changed, and increasingly she was doing other things as well, just trying to run the business side of the magazine while having a hand in the editorial content--at least reading it, because it's always good to have another set of eyes read it. But basically I organized it, planned it, and developed it.

In a small office like ours everybody pretty much had a hand in everything also. There were four of us in the San Diego office. I was doing the editing and organizing of that. We had a graphics person who also helped on reading copy and raising questions about it, and who was also doing the layout inside of the magazine. We had another woman who was kind of a support person and did circulation management and who often proofread the magazine and was involved that way and questioned things. Cynthia read it as well for attitude and other issues. So everybody did things. I did a lot of work also in developing circulation and advertising promotions and making that happen.

We had a second office in Boston where our advertising director lived and worked. She came to us in 1990 from another publication that was in Boston, Exceptional Parent magazine. She did not want to move to California, so she operated out of an office there. We subleased space out of different offices. So she was not involved so much in the day-to-day stuff of what went into the magazine, but certainly was vocal in critiquing the magazine after it arrived from the printer.

Increasingly it worked out that Cynthia relinquished control after '93. She was interested in what went into the

magazine, and we certainly discussed major activities in the magazine thoroughly because she has a real depth of background and she has contacts that are far wider than mine because she's the one who does most of the traveling outside and back to Washington. She knows a lot of people and has been to a lot of things through the seventies and into the eighties, where I wasn't really part of that.

O'Hara: Did you see the suspension coming?

Stothers: I had decided about two and a half or three years ago that I thought it probably might be happening, and it became my goal to sell the magazine. It was probably in '96 that it might have been a high water mark and that we really ought to do this, because it was taking increasing energy and resources from us. I saw no bright sun in the future. It struck me first that it was something that we had to find a way out of. That either meant selling the magazine primarily, or selling a large chunk of it in order to get capital investment. The magazine as a business was so undercapitalized that it was basically limping along holding its own. And if you don't have the resources to put into it, you can't really make it grow. We didn't have the resources to make that happen. I thought somebody else might have that, and I thought it was a viable entity that could thrive maybe under new hands. Maybe somebody would take it over and keep us under contract and buy it outright, or someone would just buy it and take it.

I believed--and I still believe--that the mission of the magazine was really to reach out to help connect people with disabilities to the movement and the community and to build a sense of community. We don't have to do that; maybe we can't do that. But maybe somebody else could do that. The magazine was a good vehicle for making that happen. To survive it was necessary to be in other hands. But that's easier for me because I don't have that visceral connection that Cynthia has with it. She was there at the beginning. She slaved down there and spent days and days at the beginning. She really believed in it, too, and she believed in what it could be. I think she identified so closely with it that it has been and was a much more difficult decision for her to try to reach this point where we had to close it down or try to sell it.

Whether anything will yet come of it, who knows? We've been very careful to say that we haven't closed Mainstream down, but that we have suspended publication with the possibility that it could always resume.

Justin Dart Article

O'Hara: There was one article that I found extraordinary that I wanted to ask you about. It might have been early last year. The article on Justin Dart. It certainly was the most thorough--it wasn't a puff piece, and it has marvelous photographs. How did you do that? It was far better than anything else I've ever seen.

Stothers: In some ways, this was a sore point because Justin came to us a year earlier, that he wanted to do this piece. And we had long wanted to do a piece on Justin as well. But this was to be Justin's testament. Basically Justin wrote this himself. This was Justin on Justin. Many hands played a role in it and many drafts were written. In fact, I wrote one of them. Fred Pelka, who has written for us a lot, is a writer with a psychiatric disability in New England, wrote a draft. In fact, he went to work for Justin and was helping with that. Fred Fay, who was very close to Justin in Concord, also was involved in it. So many hands shaped this. It basically was Justin's recitation and reflections on his own life, done in a third person sort of way. As you remember, there were three pieces: there was the long narrative piece, and then there was an open letter from Justin, and then there was a list of a hundred people who had meant the most to him.

Justin is known, of course, for his thanking everyone. Every presentation he makes he thanks everybody in the world, particularly those who are present in any given situation. Justin provided the photographs, although we commissioned the cover photo at the Lincoln Memorial and some other ones that were in his apartment. He had the rest; they were all historical things that he found. I thought it was marvelous. It really was, I think, a great document. In some respects it's similar to what your project is doing. It's Justin trying to put down everything that he can remember about his growth and development as an advocate.

O'Hara: I can't remember specific parts of it exactly now, but it seems to me that there were occasional moments in there that would not be particularly favorable on Justin. I wasn't really expecting exactly what he had written.

Stothers: No. He was and I think is hard on himself about the things that he did that were not correct. He was trying in a sense to make amends for that and to acknowledge his imperfections because he has heard so much about his idolized position, if you will, that he has been made such an icon in the movement

that he wanted to say, "I have feet of clay here. You have to see that I am not perfect. And if I can do this, you can do this." That's what he wants people to understand.

I have to say that I was very happy the way it turned out as a magazine for us. The difficulty was that in the same issue everybody else did it. The same month New Mobility put out the Justin Dart story on their cover.

O'Hara: Much shorter.

Stothers: Yes.

O'Hara: Less detailed, fewer photographs.

Stothers: Yes. Justin had talked about exclusivity in doing it for us, and we looked at it and I have to say that we had really counted on this as being something which was going to help us do better or make a better breakthrough and be better known. But when everybody does it, and just about all the magazines had something on this at the same time--

O'Hara: Why did everybody do it?

Stothers: Because Justin talked to them. We can only believe that Justin, for whatever reason, decided to be an equal opportunity kind of presenter. We had tried to do it earlier, but he had put it off and put it off. Justin, the consummate media-wise guy, indicated that in fact he didn't know that they were going to do this at the same time. He told them they couldn't do it because he was working with us. We don't really buy that. But the fact is we do think--

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O'Hara: You were saying the truth is that Justin contributed to the production.

Stothers: Right. Not only did he provide most of the photographs but he also helped pay for the production of that issue of the magazine because it was such an enormous project and took up so much space in the magazine. It was something that we just couldn't underwrite. So he did that by buying a lot of copies of the magazine, which was great, too, because he sent it out to a lot of people. I guess what hurt us in an emotional sense, what hurt our feelings on it, was that one of the things you really want to do with a publication is establish identity. It's hard in this industry to establish identity and keep it. When you have a pool of writers, each of whom writes for a lot

of different publications, then people begin to not be sure where they saw something. Very often they don't anyway. We tried to keep a stable of writers that would be identified with Mainstream. We didn't pay enough money to people to be a career for people.

But it was my hope that the people we had writing for us would be able to write for the mainstream media as well. I really encouraged them to do that. But there are some people who were writing often for us and/or New Mobility and/or Paraplegic News or Enable or what have you. I think when that happens readers then can't remember where they saw something. Also, and this is a prime example where you've got the Justin Dart story appearing everywhere, the benefit that we would have gained from the exclusivity of that was all lost. What happens is that it's not only where people say, "I can't remember which magazine I read this piece in by this particular writer," but also it means that if you call up an advertiser because you're interested in a product and they say, "Where did you see it?" and then they say whatever magazine pops into their mind or whichever has the strongest image in their mind or perhaps the last magazine they happened to look at, they say, "Oh, it was in Paraplegic News," when it may have been Mainstream or New Mobility. That then affects your advertising base. People try to find out which ads are working for them in which place. They're going to put their money in the most productive areas.

Mainstream Accomplishments

O'Hara: What are you most proud of in your fourteen-year career at Mainstream?

Stothers: I think what I'm most proud of at the magazine is the consistency with which we stuck to what we wanted to do in trying to portray the disability experience, not entirely in a strident advocacy way but in a broader way of trying to live one's life in a positive way, that people can be successful. They can have rich, engaging lives and they can be activists if they want to, and that there is a real place for activism. There's a place to go into the street and get arrested, but not everybody has to do that. But everybody can vote and should vote. Everybody can take responsibility for a lot of their own decisions and the way they live their lives. They can act positively and proactively, if you will. That's something that ought to be done, and we ought to spread that message as widely as possible.

That's the kind of vision that we tried to portray. Pretty much, I feel very happy that we did that. I'm actually very happy with the writing I did. It's very interesting because in all my years of working, when I was on the rewrite desk, I was rewriting other people's material when I began my career, and then I was pretty much an editor. I wrote headlines, and I was an excellent headline writer, I must say. The one real talent that I displayed in the newspaper business was being able to write headlines.

O'Hara: It's a hard job.

Stothers: But I'm also pretty proud of the writing I did for the magazine. The columns that I wrote were explorations of myself, I think. And I think the strongest ones were the personal columns which were exercises in reflection and self-examination of where I was and how I changed and why I changed and being able to be self-revelatory without wincing too much. In a sense it's kind of being vulnerable in acknowledging good things and bad things, that we're not always nice or pleasant. They're lessons learned. And parts of my life, maybe I wouldn't have done it that way if I had a chance to do it again, but I can at least embrace it that it was my life.

Center for an Accessible Society, 1999

O'Hara: And now on to the Accessible Society Action Project. Are you going to call it ASAP?

Stothers: Yes. In fact we've done a preliminary logo design. It's ASAP in a typeface that almost looks like a fast handwriting with an exclamation point at the end. It's the Accessible Society Action Project--as soon as possible. [Note: the name has been changed to Center for an Accessible Society. --ed.]

O'Hara: It's a great double play.

Stothers: I think it really is important. One of the things we learned from Mainstream, from all of those fourteen years--I really honor those years and what we did with the magazine--our inability to really make it succeed in the sense of having a magazine with a subscription base of a million or more readers, of people with disabilities in this country. That would mean that we were really saying that people were responding and we were achieving the goal we had set out to achieve, which was to make the movement grow by involving more people into the disability movement.

O'Hara: What is ASAP?

Stothers: ASAP is a program that is trying to do the same thing that we were trying to do with Mainstream, but by doing it in a different arena. Studies have shown that most people--over 75 percent of people--with disabilities get their information of all sorts from the popular mass media. Therefore, it's our thesis that that's where information on disability and independent living needs to be for people to get it. It will be kind of mixed in with all the other information they get, and if you see that information in your daily newspaper or on TV or in magazines, I think it might be easier for people to see, understand, and maybe even relate to in some way. Even if they don't embrace it and claim disability pride, they can say, "Hey, if I did that, my life would be better." If we help people live better lives, then we will have done something worthwhile.

Our strategy will be to try to work with the mass media to cover disability issues. Everything from universal design and maybe income policy or whatever. Maybe I should state that in a different way. What we're first of all commissioned to do is to look at the research on independent living that is funded by NIDRR, the National Institute on Disability and Rehabilitation Research. There are some 300 current projects out there that we are going to look at, talk to the people doing those projects, and see what information is there that we can somehow help disseminate through the mass media so that it would be more accessible to people who might be able to use that information.

O'Hara: This is a project funded by NIDRR?

Stothers: Yes, for five years.

O'Hara: You and Cyndi proposed this to NIDRR as your project?

Stothers: We proposed this. It's our project. Cyndi and I and Mary Johnson, the editor of the Ragged Edge, did this proposal. Cyndi is the principal investigator, and Mary and I are the deputy directors of the project. Our intention is to look at the research and try to find information that we, as journalists, think would be valid and newsworthy information that should be broadcast more widely in other media. We're going to try to develop that information and then try to get it into what we have described as the national agenda-setting media outlets for the media. By that I mean organizations such as the New York Times, the Wall Street Journal, the Washington Post, the Los Angeles Times, and maybe a few other bigger

newspapers, and magazines like Time, Newsweek, and U.S. News and World Report, and CNN, NBC, and the other networks.

By example, my own experience in the newspaper business is that every night the New York Times puts out a bulletin which says what it's putting on its front page. It tells you what the stories are and gives you an outline of what it views as the big news of the day tomorrow. That bulletin is awaited by most newspapers in the country because they want to know what the New York Times thinks is important. They don't slavishly follow it, but they certainly pay attention to it, and it influences decisions about what goes on the front pages and gets prominent display in other newspapers. Therefore, if we can get the New York Times to cover disability issues or independent living issues, especially in the context of legitimate public policy or public debate, then other papers will pick it up and follow it.

O'Hara: What would be your mechanism for doing that?

Stothers: We are in the process now of seeking proposals from national PR or media relations firms that have track records in advocating or helping organizations and businesses get their messages in front of reporters and editors.

O'Hara: What kind of problems do you anticipate?

Stothers: First of all, things happen as a result of relationships. If a PR company--or someone who works for a PR company--has a good relationship with a reporter, then he gains credibility. That means not that he's trying to PR or snow somebody--I mean, you have to be pretty upfront with people and candid--and I think that we need to be candid with what we're doing as well, and going to people with legitimate stuff. But if there are downsides to it, we have to say what the downside is. I think we just have to say we believe this is interesting material that is useful material, newsworthy, interesting, and it affects a lot of people and should be paid attention to.

I think the problems potentially arise in the understanding that people we contract with have of the issues. If the firm we hire really doesn't understand disability issues, then the misunderstanding would be conveyed through the media, and we don't want to do that. That's our biggest challenge, it seems to me right now: to find somebody to do this job that we feel comfortable with and confident that they will understand it well enough to convey the kind of vision of an accessible society that we're going to outline to reporters and sell it well enough without falling into the traditional traps of the

traditional stereotypes of charity and pity and that we're overcomers--that they really sold them in a different way.

One of the other things that we expect this firm is going to do is to try to relate to us intelligence from newsrooms. This is one of the great things that PR firms can do. Act as, if not spies, then as intelligence officers who can find out what people are thinking and the kinds of things that they're looking at. Attitudes about disability--I think that it is very important to find out--what people think about this stuff. It may be very difficult to change somebody's mind if they have a very negative issue about disability. That's the kind of stuff we want to work on.

If a person for the New York Times or some other big newspaper is developing a series of articles or examining a certain topic where we think that there is a legitimate disability perspective, we would want to know that this is going to be happening so that we could provide that kind of perspective, and, hopefully, that it will be included. There's no guarantee that we're going to be successful at this, because you can lead a horse to water but you can't make him drink. But if we consistently put quality information and ideas before people, I think that we have a shot of beginning to make some headway on this.

O'Hara: How did this idea germinate? Who thought it up?

Stothers: I think Mary thought of it and we thought of it independently. I've long thought that--and Mary did equally--we need to get our message out the way everybody else does in the country. This is the way the world works.

O'Hara: Are you going to be dealing in television as well?

Stothers: I think they will be, yes. Part of the problem is that the amount of money that we have to spend is minimal. Therefore, this is a hard job. It's a long-term hard job. We have no illusion about that. The danger is that when you hire somebody, and in their push and desire to succeed and be seen to be doing something, like they're not wasting your money, that they might waste your money by trying to generate stuff. That isn't necessarily appropriate. We're very clear on what we want to do. We don't want somebody to go out and spend \$50,000 doing videos.

I don't think we want to spend our money that way. We want to spend our money really doing conceptual stuff, and I think that if it really comes down to making things work in the print

media, which I think is what we feel most confident with, TV will try to develop it in some way. And we can provide the sources for this, which is another aspect of the project. As we talk to NIDRR projects and find out what they do, we are in effect interviewing them in two ways. First of all, to find out what they're doing but also evaluating the people from those projects as potential spokesmen or experts who could be contacted by reporters. If, for instance, somebody is doing a project on farmworkers or whatever, if somebody needed an expert on that with a disability spin to it, we could find a researcher who was articulate on that issue and put those people in contact. We would feel good about that if the person really was able to react well and interact with a media person.

There are some researchers who are very wary and reluctant to deal with reporters because they think reporters get it wrong or might get it wrong. Well, that's the way life is. On the one hand, maybe there's a 20 percent chance that they will get it wrong. But if you don't talk to them there's a 100 percent chance that they won't get it right. Sometimes you have to take the risks. Hopefully, we will be able to work with researchers to help them respond and assess their ability and to give soundbites and good quotes. But, also, we are going to selectively pick people for our media firm to train them in dealing with the media.

The other aspect of that, which ties into both of those things, is that we're going to be doing kind of a media watch by looking at the newspapers and watching TV news programs, and what issues are out there that are alive. For instance, just out of this conference now, there are all these cases at the Supreme Court that are going to come out by June. It's a wonderful opportunity for us to be looking at people who are experts in these areas. We can spend time, now, trying to develop different scenarios that if the decisions are positive for our side that they can talk about the importance of the victories and the implications of them for people with disabilities. Or the flip side. What are the implications if we lose, and the dangers involved? We're going to be ready to provide information to reporters in the national media with articulate experts to say things right away, and also material that talks about the implications for our side. We know that people on the other side are doing the same thing and are well prepared. You can see it in the past, in the reactions to some of these court cases that come out.

So if we can do that kind of thing, we become transparent. Our job is not really to be the spokespeople. Our job is to put media people in touch with the real experts, and,

hopefully, that the message about independent living is going to get into the media and, therefore, to the people in a legitimate and credible way. I think if people see good information about real issues, then I think that they can, hopefully, buy into it. There is a lot of political stuff or policy issues that aren't necessarily going to activate anybody to do something. But there are things such as universal design issues that can specifically indicate their applicability for a wide range of people that I think would be real possible to do, and those kinds of stories are going to be done also.

Closing Thoughts

O'Hara: Sounds like it's a critically important, complicated, and fascinating project.

Have we left out anything that you were planning to say this week?

Stothers: We've talked a lot about from where I started to where I am now. I'm almost fifty-nine years old, but in some ways I have never felt better in my life about myself. I've never felt better about being a person with a disability. I often say this to people--I'm going to sound kind of lecturing or preaching here--there's never been a better time in the history of the world to be a person with a disability. There never has been. Whatever the problems are--it can be a lot better--but right now it's a better place. And we've had a lot to do with that happening. And a lot more can be done. I think that it's a time of opportunity. It's a new millennium. I think anybody involved in the disability rights movement has to be proud of where we are. For all the fights and bickering that goes on and the backbiting and all the terrible stuff that goes on--.

We did this story several years ago about a little kid who had severe CP and he was going off to kindergarten. We sent a woman with severe CP to interview him, to do a story on him. This little kid--whose name was Andy--freaked out. He freaked out because when he saw Pam coming to interview him, he realized that that's what he was going to grow up to be as a person with severe CP. It was like a recognition of the future in himself. He wouldn't talk to her. But we did the story anyway. We got the story done, and Andy's family is really great.

Andy's here. He's a sophomore at Cal now. A brilliant kid. He uses a power-driven wheelchair. His arms are strapped to his armrests. He controls his chair by using his head; he's very spastic. He won a full Regents scholarship to Berkeley. He's a brilliant kid. He's got the whole world ahead of him. He wants to work in the White House. And he can, you know? It blows me away. And we've helped that happen. I think people like Andy, while there are a lot of people that we can't identify as the new generation of leaders, I think we have to hope that they're there. I think, maybe, people like Andy are there and that people will find a way. Maybe we're just getting old and worried that [in a gruff voice] "these young kids can't do stuff." I guess that's all I have to say.

O'Hara: Historians of future generations thank you, Bill.

TAPE GUIDE--Mainstream Magazine: Chronicling National Disability Politics

Interview with Cynthia Jones

Interview 1: March 11, 1999

Tape 1, Side A	1
Tape 1, Side B	11
Tape 2, Side A	21
Tape 2, Side B	32
Tape 3, Side A	42
Tape 3, Side B not recorded	

Interview 2: March 14, 1999

Tape 4, Side A	58
Tape 4, Side B	67
Tape 5, Side A	76
Tape 5, Side B	87
Tape 6, Side A	95
Tape 6, Side B	109

Interview with William Stothers

Interview 1: March 10, 1999

Tape 1, Side A	126
Tape 1, Side B	135
Tape 2, Side A	144
Tape 2, Side B not recorded	

Interview 2: March 11, 1999

Tape 3, Side A	153
Tape 3, Side B	162
Tape 4, Side A	171
Tape 4, Side B	179

Interview 3: March 14, 1999

Tape 5, Side A	185
Tape 5, Side B	194
Tape 6, Side A	203
Tape 6, Side B	211

INDEX--Mainstream Magazine: Chronicling National Disability Politics

- Abilities Expos, 115, 205
 Able Disabled Advocacy, 58, 65-67, 71, 203. See also *Mainstream* magazine
 Accent on Living, 98, 114
 accessibility (or lack thereof), 7, 10, 18-20, 27, 51-52, 55-57, 58, 75, 94, 95, 102, 105, 107-110, 112, 119, 146-147, 150, 151, 156, 163-164, 174, 177-180, 197, 200. See also transportation
 acquired immune deficiency syndrome, 2, and disability rights movement, 100-101
 Action League for Physically Handicapped Advancement, 152, 177-185
 ADA. See Americans with Disabilities Act
 Adams, Larry, 20, 26, 44-45
 ADAPT. See American Disabled for Accessible Public Transit. Now called American Disabled for Attendant Programs Today
 affirmative action, 115-116
 AIDS. See acquired immune deficiency syndrome
 Air Carrier Access Act, 81
 alcoholism, 150, 163, 166, 172, 176, 207
 Allen, John (bishop), 40
 ALPHA. See Action League for Physically Handicapped Advancement
 American Disabled for Accessible Public Transit, 80-81, 84, 89, 96, 200
 American Public Transit Association, 84, 96
 Americans with Disabilities Act, 90, 92-109 *passim*, 201
 anti-war demonstrations, 30-32, 166-167
 APTA. See American Public Transit Association
 architectural barriers, 51, 53, 171, 181-183, 192. See also accessibility
 Architectural Barriers Act of 1968, 192
 assistive devices, 71, 219; braces, 3-4, 141-142; crutches, 5, 78, 82, 97, 140-142; iron lung, 2, 88, 130; scooter, 78-80, 82, 97-100. See also technology
 attendant work, 75, 99, 155, 156, 168, 179
 Bacon, Betty, 201
 Bartlett, Julian, 44
 Beirneschke, Ralph, 74
 Bellwoods House, Toronto, 177-179
 Berkeley, California, impact of, 152, 165-168, 173-174, 181-182, 207. See also University of California, Berkeley
 blind community, 91, 98, 111, 113, 188
 Bouvier, Elizabeth, 81, 118
 Bragdon v. Abbott, 101
 Bristo, Marca, 84-85
 Bush, George Herbert, 87, 90, 92-93, 96-100
 Califano, Joseph, 49
 California Association of the Physically Handicapped, 44-45, 81
 California State Department of Rehabilitation, 26, 50, 96, 199
 camp, summer, 21-22, 150-152, 156
 Campfire Girls, 15

- CAPH. See California Association of the Physically Handicapped
Case Manager Review, 116
 Caulkins, Phil, 82, 83, 86-87, 89-90
 CCD. See Consortium of Citizens with Disabilities
 Center for an Accessible Society, 117, 119, 213-218
 Center for Independent Living, Berkeley, 96, 182
 cerebral palsy, 8, 22, 45, 65, 80, 91, 177, 179, 189, 218-219
 Cheever, Ray, 98
 Chipman, Jennifer, 79
 cigarettes, use of, 144, 161
 CIL. See Center for Independent Living
 civil rights movement, 19, 23, 30, 32-34, 37, 40; parallels with disability rights, 33; Watts (1965), 10-11, 32, 37, 40
 Coleman, Diane, 95
 Community Service Center for the Disabled (CSCD), 198-199, 200-202
 Consortium of Citizens with Disabilities, 94
 Cook, Tim, 82, 86-88, 93
 Crabb, Nolan, 98
 Crase, Cliff, 98
 Crase, Nancy, 77
 Crombie, David, 185-186
 cross-disability inclusion, 8, 45-47, 91-92, 111, 113-114, 144-145, 151-152, 177-179, 187-188
 curb-cuts/ramps, 46, 47, 56, 75, 79, 88, 163, 178-179, 184, 185

 Dart, Justin, 82, 92-93, 95, 101, 117, 201, 210-212
 deaf community, 91, 98
 Democratic Party, 87, 89-90
 Department of Justice, United States, 102, 108-109
 developmental disabilities, 91, 129
 disability, and athletics, 72-73, 75-76, 109-114, 196
 disability, and driving, 24-25, 54, 65, 143-144, 196. See also parking spaces
 disability, and education, 11-12, 25-32, 65, 89, 94, 95, 117-118, 135, 138, 148, 151-157, 177-179, 182, 218-219;
 mainstreaming, 7, 9-10, 13-16, 18-21, 23-25, 145-147, 149-150
 disability, and employment, 15, 28-29, 45, 47-49, 54-55, 65-67, 74, 85, 94, 95, 99, 157-162, 174-176, 181, 203
 disability, and housing, 55-56, 58-59, 71, 95, 99, 138, 139, 179-181, 197-198. See also accessibility
 disability, and marriage, 53-57, 65, 148, 177, 189-190, 195-196
 disability and sexuality, 71, 171-173
 disability, and the elderly, 184-186
 disability, and travel, 172, 175, 189, 190
 disability, attitudes towards, 6, 8, 12, 15, 19, 20, 22, 29, 66, 71, 91-96, 117-120, 129, 133-138, 141, 144-146, 149-150, 151-152, 154-155, 161-162, 169-170, 172-180, 182-186, 195-197, 199-200, 204-205, 207, 209, 215-219
 disability culture, 102, 212-213
 disability, diagnosis and progression, 1-5, 120-121, 130-143
 disability, establishing independence, 71-72, 81, 137, 138, 139, 143, 144, 169-174, 177-184
 disability, experiences with discrimination, 38-39, 43, 47-48, 64, 74, 75, 95, 103-109, 146-148, 155, 182

disability, family response and reaction, 1-2, 4, 6, 8-10, 12-13, 90-91, 94, 120-121, 128, 131, 133, 134-135, 138, 148, 150

disability, identity, 8, 22, 29, 45, 56, 71, 81, 88-89, 91-92, 101-109, 147-148, 151-152, 173-174, 207, 218

disability, perceived hierarchy, 91-92, 113-114, 188

disability, political action, 71-72, 87-88, 92-96, 101-109, 178-180, 182-186, 191

disability rights, 62, 91, 101-102; as a civil rights issue, 52, 92-93, 104-109, 188

disability rights movement, 6, 44-45, 71-72, 88-89, 92-109, 117-119, 137, 187-188, 191-192, 197-199, 204-207, 209, 213-214, 218

Disability Programs and Reports, 98-99

Disability Rag, The, 80, 82, 84, 90, 206, 214

Disability Rights Education and Defense Fund, 73-74, 82, 96, 113

Disabled in Action (DIA), 179, 181, 182

Down's syndrome, 120-121, 155

DREDF. See Disability Rights Education and Defense Fund

drug use, 166

Dukakis, Michael, 87, 92-93

Easter Seals, 21-22, 183

EEOC. See Equal Employment Opportunity Commission

Enable, 114, 115, 212

Episcopal Church, 12, 38-40, 54, 62-63, 99, 190; gays in, 62-63; ordination of women, 38, 40-44, 62, 82; Women's Caucus, 40-44

Equal Employment Opportunity Commission, 74, 102, 115-116

euthanasia, 118

Exploding Myths, Inc., 78, 203-207. See also *Mainstream* magazine

Fay, Fred, 87, 210

Fleming, Andy, 72

Funk, Bob, 73-74, 82, 83, 84, 89, 96

Gallagher, Hugh, 192

gay and lesbian issues. See sexual orientation

Gingrich, Newt, 106

Globe and Mail, 157-162, 174, 175

Golding, Susan, 106

Griswald, Martha, 80

Hamilton, Marilyn, 113

Hammitt, Jim, 8, 44-46, 49, 51, 52, 65, 71, 189, 203

Hamrick, Royce, 201

Hanchett, Tom, 68

Handicapped Postcards, 115

Havens, Thomas, 162

Hayward, Carter, 62

health insurance, 2; in Canada, 181

health maintenance organizations (HMO), 116

Hedrick, Sharon, 76-77

Hessler, John, 170, 173-174

Heumann, Judy, 52, 181, 201

Higa, Martha, 79

Hines, John (bishop), 40

Hollenbeck, Scott, 111

Hudak, Ed, 88

IDEA. See Individuals with Disabilities Act

immigration issues and citizenship, 57, 190-191

independent living concept, 80, 89, 117, 173-174, 177-184, 191-192, 217-218

- Independent Living Center, San Diego, 105, 107, 198-199, 200; Toronto, 183
- Individuals with Disabilities Act, 9, 118
- Institute of Medicine (IOM), 99
- International Business Machines (IBM), 159
- Jameson, Kahlil, 105
- Johnson, Mark, 82, 84, 95, 112
- Johnson, Mary, 80, 84-85, 214, 216
- Johnston, Ann, 184-186
- Jones, Cynthia, Int. 1-121, 189-190, 192-193, 201-203, 207-209, 214
- Jones, Erica, 94
- journalism, 54-55, 71-72, 87-88, 151, 156-162, 174-176, 179-180, 184, 186, 193-197, 199-200, 207-213, 214-218. See also media, publications by name
- Jouse, Allan, 144
- Kafka, Bob, 80
- Kailes, June, 74
- Kellerman, John, 179
- Kemp, Evan, 73-74, 82, 84, 87, 89-90
- Kennedy, Bobby, 32-33, 167
- Kennedy, John F., 32
- King, Martin Luther, Jr., 32-33, 62
- Lazrey, Lynn, 107
- Lee, Jonathan, 46-47
- Longmore, Paul, 207
- Lyndhorst Lodge, Toronto, 143-145
- Mainstream magazine, 8, 45-52, 58, 64-81, 84-101 *passim*, 105-106, 109, 112-120, 189, 195, 197-198, 202-214 *passim*
- mainstreaming. See disability and education
- Mansfield, Gordon, 83
- March of Dimes, 5-7, 183
- Marchand, Paul, 94
- Martinez, Kathy, 84
- McAfee, Larry, 98
- McGovern, Frank, 45-46, 65
- media, 104-108, 112-115, 214-218. See also individual publications by name, journalism
- Medicaid, 98
- minorities, discrimination of, 32-33, 37, 104-105
- Mouth, 206
- Murray, George, 73, 74
- muscular dystrophy, 91
- National Aeronautics and Space Administration (NASA), 18-19
- National Council on Independent Living, 85
- National Council on Disability, 85
- National Institute on Disability Research and Rehabilitation, 117-119, 214-218
- National Institutes of Health, National Center for Rehabilitation Research, 99
- National Wheelchair Athletic Association, 72
- NCD. See National Council on Disability
- NCIL. See National Council on Independent Living
- New Mobility*, 113, 118, 206, 211, 212
- New York Times*, 214-216
- NIDRR. See National Institute on Disability and Rehabilitation Research
- Nossal, Frederick, 160-161, 162
- Olympics, 73, 75-77, 108, 109-110, 115

Owen, Bill, 177-178, 183-184
 Owen, Mary Jane, 84, 86, 89
 Ozols, Andy, 66-67, 69

Paralympics, 75-76, 109-115, 118
Paraplegic News, 98, 114, 206, 212
 parking spaces, disabled, 103, 107-109
 Peace Corps, 38-39
 Pelka, Fred, 210
 PILCOP. See Public Interest Law Center of Philadelphia
 polio, 1-5, 28, 91, 128-143, 154-155, 177
 post-polio syndrome, 79-80, 88, 144, 177, 193
 President's Committee on Employment of the Handicapped, 85
 Project SEED (Special Elementary Education for the Disadvantaged), 37
 psychiatric disability, 91, 210
 Public Interest Law Center of Philadelphia, 87

Ragged Edge, The. See *The Disability Rag*
 Reagan, Ronald, 62, 64, 66, 203
 real estate, practice of, 55-56, 58-64, 66-67, 197
 reasonable accommodation, 5, 28, 34-35
 Reeves, Christopher, 111
 Regional Employment Training Consortium, 45-46, 50-51, 65
 rehabilitation, personal experiences with, 2-4, 132-145. See also spinal fusion
 Rehabilitation Act of 1973, San Francisco sit-in, 49-50, 72, 187; Section 504, 25, 49-50, 92, 102, 103, 187
 Rehabilitation Institute of Detroit, 143

Rehabilitation Services Administration, 93
 Republican Party, 74, 89-90, 106
 RETC. See Regional Employment Training Consortium
 Roberts, Edward V., 50, 52, 89, 96, 169, 170, 173-174, 182
 RSA. See Rehabilitation Services Administration

San Diego, disability community in, 103-106, 200-202
San Diego Union Tribune, 54-55, 66, 81, 101, 105-106, 190, 193-199, 202
 Savage, Elizabeth, 96-97, 100
 Sawhney, Nancy, 75
 Section 504. See Rehabilitation Act of 1973
 sexism, 82-88
 sexual orientation, 62-64
 Shapiro, Joe, 98, 99
 Shriners' Hospital, Los Angeles, 10-13, 16
 Sister Kenny Hospital, Pontiac, MI, 138-139
 smallpox vaccine, 15
 South, Cal, 62-64
 spinal fusion, 3, 10-14, 16-18, 134
 spirituality, 38, 44, 55. See also Episcopal Church
Sports and Spokes, 77, 114
 SSI. See Supplemental Security Income
 Starkloff, Max, 82, 86
 Stone, David, 80
 Stothers, William, 20, 52-57, 64, 66, 75, 77-79, 81, 91, 92, 101, 103, 105-106, 117, 120, 121; Int., 126-219
 substance abuse, and disability, 207. See also alcoholism
 Sunrise Medical, 112-113, 115
 Sunshine School, San Diego, 8-9, 20, 26, 45, 47, 65
 Supplemental Security Income, 26, 99, 197

- Tainter, Bill, 199
 technology, electric typewriter, 158-159
 Thistletown Rehabilitation Center, Toronto, 132-138, 140, 141, 145
 Toronto, Ontario, Canada, accessibility of, 177-186, 192-193
 Toronto Star, 54, 174-177, 179-180, 197, 200
 Toronto Transportation Commission, 182
 transportation, accessible, 47, 54, 65, 71-72, 75, 80-81, 84, 92, 95, 102, 146, 170, 172, 176, 179-183, 185, 190
 typewriter, electric, 158-159
- Ueberroth, Peter, 75
 United Cerebral Palsy Association (UCPA), 20
 University of California, San Diego, 25-32, 34, 38-39, 43-44; lack of disabled services at, 27-28, 35-37; scholarship for, 23
 University of California, Berkeley, 152, 162-168, 182, 219; Cowell Hospital Residence Program, 169-174, 177, 182; International House, 163-168, 171-173
 University of Toronto, 161-162
 University of Western Ontario, 153-157, 166
- Valdez, Richard, 107
 Vaughan, Michael, 155
 Vietnam War, 19, 23
 Vincelett, Carol, 47-48
 Vocational Rehabilitation, Department of. See California State Department of Rehabilitation
 Volpentez, Tony, 114
- Walker, John (bishop), 40
 Warm Springs, GA, 139-143, 145
 Warren, Gerald, 190
 Watkins, Rich, 48
 We, 114, 115
 weight issues, 13, 43, 79-80
 Wellman, Mark, 111-112
 Wertz, John, 109
 Wetzel, Terry, 22, 37
 wheelchairs, lightweights, 75; manual, 12, 14, 80, 132, 141-142, 146-148, 164, 167-168; power, 28, 51-52, 71, 91, 168-170, 173, 177-180, 182-183, 188, 192-193, 219
 White House Conference on Handicapped Individuals, 1977, 49-52, 54, 72, 84, 187-189, 191, 200
 Winter, Michael, 96
 Wolfe, Kathy, 113
 Wolinsky, Sidney, 107
 Wolterstorff, Bishop, 43
 women's issues, 34, 38. See also Episcopal Church, sexism
 Wooten, Richard, 44
 Wright, Patrisha, 84
- Yaeger, Patricia, 105, 199
- Zola, Irving, 89
 Zola, Ken, 80
 Zorn, Trish, 111

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Disability Rights and Independent Living
Movement Oral History Series

Mary Lou Breslin co-founded the Disability Rights Education and Defense Fund (DREDF), a national disability rights law and policy center established in 1979. She has served as DREDF's deputy and executive director, and president and chair of the board of directors. She is currently a member of the board. She spearheaded that organization's leadership in the enactment of such landmark legislation as the 1990 Americans with Disabilities Act (ADA), Fair Housing Amendments Act, and the Civil Rights Restoration Act. In 1993 she founded the DREDF Development Partnership, a corporation dedicated to supporting and securing DREDF's programs. During her twenty-five year career she has served as a policy consultant, trainer and lecturer on diverse disability and related civil rights topics including working with disability rights leaders in Russia, Bosnia-Herzegovina and Japan on strategies to further the rights of individuals with disabilities in those countries.

Since 1997 Ms. Breslin has taught at the University of San Francisco (USF), McLaren School of Business, Executive Master of Management and Disability Services program. She also serves as senior investigator and consultant with USF's Disability Leadership Archival Research Project, and editor, researcher, and interviewer with the Disabled Persons' Independence Movement Project of the Regional Oral History Office of the Bancroft Library, University of California at Berkeley. She is presently a senior policy advisor with DREDF. Ms. Breslin received a Mary E. Switzer Merit Fellowship in 1995. Ms. Breslin had polio as a teenager and uses a wheelchair.

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